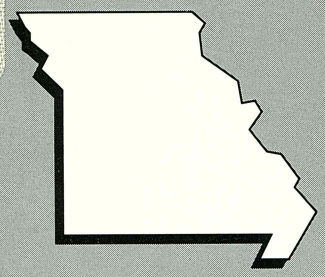

FY 90

Missouri
Head Injury
Advisory
Council

Annual Report and Action Plan for Services

Missouri Office of Administration

Missouri Head Injury Advisory Council

FY' 90 Annual Report

and

Action Plan for Services

Covering activities of the Missouri Head Injury Advisory Council from July 1, 1989 through June 30, 1990.

John Ashcroft, Governor
State of Missouri

James R. Moody, Commissioner
Missouri Office of Administration

Stan Perovich, Director
Division of General Services

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May 1991

Forward

The Missouri Head Injury Advisory Council was created by Executive Order in 1985, at the recommendation of a legislative Joint Interim Committee on Head Injury, and established in law in 1986, to study the unique rehabilitative and service needs of survivors of head injury and their families. The council, established under Section 192.745 RSMo, is comprised of members who represent the Missouri General Assembly, consumers, family members, professionals, and state agencies administering such programs as special education, vocational rehabilitation, mental health, health, public safety, medical services, insurance and vocational education.

Organizationally, it is assigned to the Missouri Office of Administration, and its charges are (1) to make recommendations to the governor for developing and administering a state plan to provide services for Missourians with head injury and (2) to report annually to the commissioner of administration, the governor and the general assembly on its activities, results of its studies and the recommendations of the council.

Specifically, the council is to be advisory and shall:

(1) Promote meetings and programs for the discussion of reducing the debilitating effects of head injuries and disseminate information in cooperation with any other department, agency or entity on the prevention, evaluation, care, treatment and rehabilitation of persons affected by head injuries;

(2) Study and review current prevention, evaluation, care, treatment and rehabilitation technologies and recommend appropriate preparation, training, retraining and distribution of manpower and resources in the provision of services to head injured persons through private and public residential facilities, day programs and other specialized services;

(3) Recommend what specific methods, means and procedures should be adopted to improve and upgrade the state's service delivery system for head injured citizens of this state;

(4) Participate in developing and disseminating criteria and standards which may be required for future funding or licensing of facilities, day programs and other specialized services for head injured persons in this state; and

(5) Report annually to the commissioner of administration, the governor, and the general assembly on its activities, and on the results of its studies and the recommendations of the council.

In keeping with the council's bylaws, the Missouri Head Injury Advisory Council held five meetings during Fiscal Year 1990. At its September meeting the council re-elected Judith Ferguson, Kimberling City, as chairman and Representative Sheila Lumpe, University City, as vice-chairman. Five committees were appointed to carry out the goals and objectives of the council as outlined in the FY'89 Annual Report.

This report provides an update of the council's progress in meeting its goals and objectives of which have been defined to meet the major goal of recommending a statewide service delivery system for survivors of head injury and their families. It is organized into two major chapters: (1) *Description of Service Model & Needs* and (2) *Action Plan Update.*

In Chapter One, an attempt is made to describe a model service system, including prevention strategies, and existing services in the state. The inclusion of known providers should not be interpreted as an endorsement of those particular services, but as an attempt to describe the current service delivery system. It is possible that services are being provided by other agencies which the council is unaware of and, thus, not included in that section. Chapter Two outlines goals and objectives, as well as progress in meeting those goals, for developing and implementing a service delivery system as envisioned by the council.

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Introduction

"Head injury" or "traumatic head injury" is defined as: "a sudden insult or damage to the brain or its coverings, not of a degenerative nature. Such insult or damage may produce an altered state of consciousness and may result in a decrease of one or more of the following: mental, cognitive, behavioral or physical functioning resulting in partial or total disability. Cerebral vascular accidents, aneurisms and congenital deficits are specifically excluded from this definition" (Section 192.735 RSMo).

Head injury or brain injury is a traumatic insult to the brain requiring extensive services over an extended period of time. Although the injury is not always visible, it may cause physical, emotional, intellectual, social and vocational changes. There are two types of head injury: closed head injury and open head injury. A "closed head injury" refers to damage that occurs within the skull after a blow to the head. Although the skull may stop on impact, the brain will often continue to whip back and forth against the skull from within causing damage. The second category of head injury referred to as "open head injury" is a visible assault and may be the result of a gun shot wound or an accident.

The symptoms of head injury may vary greatly, depending on the extent and location of the injury. The following are three types of impairments associated with head injury. Any or all of the impairments may occur in varying degrees and there may be other symptoms than those listed below.

•*Physical impairments*; including speech, vision, hearing and other sensory impairments; headaches, lack of coordination; spasticity of muscles, paralysis of one or both sides and seizure disorders.

•*Cognitive impairments*; which may result in memory deficits, either long or short term; and problems with concentration, attention, perception, communication, reading, writing, planning, sequencing or judgment. Learning problems which have been identified include decreased ability for abstraction less initiative and distractibility.

•*Psycho-Social-Behavior-Emotional impairments*; including fatigue, mood swings, denial, self-centered, anxiety, depression, lowered esteem, sexual dysfunction, restlessness, lack of motivation, inability to self-monitor, difficulty with emotional control, inability to cope, agitation, excessive laughing or crying or difficulty relating to others. Personality can be altered and the person may become argumentative or become socially withdrawn and unable to interact with peers. Often a person with a head injury will insist he or she can understand completely when in actuality is totally confused.

Referred to as the "silent epidemic", head injury has been cited nationally as the leading cause of death and disability up to the age of 44. In Missouri, hospitals reported 6,592 head and spinal cord injuries during the 1989 calendar year and 6,500 head and spinal cord injuries were reported to the Missouri Department of Health during the 1988 calendar year. The head and spinal cord injuries are overrepresented primarily among 15-24 year old individuals, and to a lesser extent, young children and older adults. Motor vehicle crashes contribute to nearly one half of all head injuries. Falls account for nearly one in four injuries reported in Missouri and are the second leading cause. Other causes include diving and other recreational injuries, industrial injuries, assaults and weapons.

Emergency medical and technologic advances have resulted in greater survival rates for persons who have sustained a traumatic head injury. The number of survivors will continue to increase as emergency medical services and hospital care, including trauma centers, continue to improve and become more readily available. The increased number of survivors has placed greater demands for rehabilitation services, long-term care, supervised residential living, vocational rehabilitation, employment, and community support programs. Many of these services are available to individuals with other disabilities, however, these services are either difficult to access or not readily available to persons with head injuries.

Federal Initiatives

In 1985, a report of the Committee on Trauma Research, *Injury in America*, documented the magnitude of the injury problem and made recommendations to Congress to establish the Center for Injury Control in the Centers for Disease Control. Although the National Highway Traffic Safety Administration and other safety organizations have provided leadership in the area of traffic injuries and fatalities for years, public health has recently joined that arena.

The Centers for Disease Control has held two national conferences on Injury in America and has placed increasing emphasis on injury prevention as a public health problem. Grants have been awarded across the country to establish state head and spinal cord injury surveillance systems, to evaluate efficacy and effectiveness of prevention programs, and to assist states in developing prevention plans.

In 1988, the U.S. House Committee on Appropriations encouraged the establishment of an Interagency Head Injury Task Force to identify the gaps in research, training and service delivery and to recommend solutions in meeting the needs of individuals with traumatic head injury. At the same time the Senate Committee on Appropriations encouraged increased efforts among federal government agencies in these areas.

The Task Force was established by the Secretary of the Department of Health and Human Services in early 1988. He appointed as its chairman the Director of the National institute of Neurological Disorders and Stroke, National Institutes of Health, and included on the Task Force representatives from thirteen federal agencies.

The Task Force issued its report in February 1989. The Task Force recommended six national strategies:

Recommendation 1: Establish "traumatic brain injury" as a category in reporting systems.

Recommendation 2: Designate a lead federal agency with responsibility for overall coordination and planning for federal, state and private sector activities and establish a government-private sector advisory group to assist the effort.

Recommendation 3: Encourage the establishment of working groups at the state and local level to provide leadership and coordination.

Recommendation 4: Create a national network of fifteen comprehensive regional head injury research centers, beginning with the immediate establishment of five centers and adding five additional centers per year for the next two years.

Recommendation 5: Organize a decentralized system of care networked with regional head injury research centers to ensure accessibility to appropriate care. Inform TBI victims and their families about the availability of such service facilities.

Recommendation 6: Study and document the financial issues relevant to patient and family services, societal cost and related economic impact of TBI.

Since the issuance of the Task Force report, Centers for Disease Control (CDC) has been designated as the lead federal agency and is responsible for carrying out the recommendations of the Task Force Report.

Summary of Fiscal Year 1990
Missouri Head Injury Adivsory Council Activities

The Missouri Head Injury Advisory Council met five times during Fiscal Year 1990 (July 1, 1989 - June 30, 1990). At its September meeting the council re-elected Judy Ferguson and Representative Sheila Lumpe as chairman and vice-chairman. Mrs. Ferguson appointed five committees to facilitate council business. She assigned to the Subcommittee on Community Residential/Employment and Support Services the task of developing recommendations for housing for persons with head injury. She also asked the Subcommittee on Rehabilitation/Long-Term Care to make recommendations for services for persons requiring extended nursing/ rehabilitation care.

Service Coordination and Expansion

The council developed goals and objectives for the Missouri Division of Comprehensive Psychiatric Services with regard to its services to clients/patients with head injury for inclusion in the Department of Mental Health's State Plan.

The council supported legislation, which passed, expanding the definition of developmental disabilities to include head injury and to increase the age of onset from age 18 to age 22. The definition determines eligibility for services provided by the Missouri Division of Mental Retardation and Developmental Disabilities and for services funded and/or provided by county boards administering funds generated by a county mill tax levy for persons with developmental disabilities.

The council had representation on the Missouri Planning Council Prevention Committee, Missouri Injury Control Advisory Committee, and the State Advisory Council on Emergency Medical Services Subcommittee on Trauma Registry.

New Services

Prevention

The State Injury Control Program was created as the result of the Centers for Disease Control grant to the Department of Health. Two council members and the council staff were appointed to the new State Injury Control Committee by the director of the Department of Health.

Rehabilitation

A new state Medicaid service came on line during Fiscal Year 1990, relating to post acute rehabilitation. As the result of state legislation which passed in 1988, "comprehensive day rehabilitation" (functional rehabilitation) for post-acute head trauma patients was added to the state Medicaid program.

The council advocated for the new service and assisted the Missouri Division of Medical Services with the development of guidelines for client and provider eligibility. The service became available January 1990, and initially three head injury rehabilitation programs enrolled in the Medicaid program.

Supported Employment

The Missouri Office of Administration, Division of General Services, as the result of receiving an additional state appropriation for long-term support services to enable persons with head injury to participate in the federal supported employment program, contracted with eight community programs for long-term support. All eight contractors are also under contract with the Division of Vocational Rehabilitation to provide supported employment services.

The Division of Vocational Rehabilitation administers federal funding for time-limited services including job assessment, job training, job placement and job coaching. Long-term support, such as job coaching, must be available in order for the person to be able to maintain employment after funding from the federal vocational program has been expended. This represents a new service for survivors of head injury.

Professional Development

The council sponsored its fifth annual statewide conference, "Entering the Decade of the Brain: Head Injury Research, Rehabilitation & Re-entry, May 1990. Approximately 150 people attended.

In October 1989, the council sponsored an in-service training workshop, "Developing Vocational and Supported Work Options for Persons with Head Injury," for vocational agencies and programs and other service providers. The two day workshop was co-sponsored by the Division of Vocational Rehabilitation and the Rehabilitation Continuing Education Program, University of Missouri-Columbia.

Public Information and Outreach

At the recommendation of the council the Missouri Office of Administration entered into a contract with the Missouri Head Injury Association for the development and dissemination of a family resource guide. The guide was a joint project of the council and the association. The 70 page guide, *Missouri Head Injury Guide for Survivors, Families, and Caregivers*, was distributed to hospitals, rehabilitation programs, advocacy organizations, mental health programs, developmental disabilities programs, and others for distribution. Ten thousand copies of the guide were printed.

The Missouri Division of Health Resources and the council developed a pilot project for purposes of contacting persons/families reported by the Missouri Head and Spinal Cord Registry in an effort to assess their needs and, at the same time, make known resources available to them. The division is to mail letters to those reported during a two month period late summer/early fall of 1990.

The council developed an Idea Sampler for head injury awareness month in cooperation with the Missouri Head injury Association and the Department of Health and distributed it to approximately 40 local organizations and agencies.

The council staff continued to publish a quarterly newsletter, which is mailed to 4,500 people, developed a service brochure, and continued to provide information and referral resources. The council also exhibited information on head injury rehabilitation and available resources at statewide conferences.

Legislation

The council supported legislation, which passed, expanding the definition of developmental disabilities to include persons who receive a head injury prior to the age of 22. The council also supported legislation establishing a high risk health insurance pool for persons unable to obtain health care coverage due to preexisting conditions.

For the second year the council supported legislation establishing a division of head injury and rehabilitation in the Department of Health. The bill passed the Missouri Senate, but did not pass the house.

The council also initiated and supported legislation to strengthen the DWI law to comply with Section 408 of the Federal Highway Safety Act. The bill did not pass. Also failing to pass, was legislation requiring the use of seat belts in pick up trucks.

Federal Grants

The Office of Administration on behalf of the council submitted an application to the Rehabilitation Services Administration for purposes of establishing a regional model head injury services delivery system. The application was supported by several agencies within the state as well as agencies in Kansas, Iowa, and Nebraska. The grant was not funded.

The council supported and assisted in the development of a federal research and demonstration grant submitted by the University of Missouri-Columbia to the U.S. Department of Education to evaluate the quality of life of persons with head injury receiving supported work services. The council also supported the application submitted by the Rehabilitation Continuing Education Program, University of Missouri-Columbia for training of supported work providers. Neither application was funded.

Chapter One:

DESCRIPTION OF SERVICE MODEL & NEEDS

Array Of Services

Overview

The Missouri Head Injury Advisory Council has defined a service delivery system model addressing all of the service components including: **Prevention, emergency medical and medical services, rehabilitation, case management, housing, and community support services.** The council has defined services and organized them into the above categories which are similar to both the medical/ health care community and the mental retardation/ developmental disabilities community.

The Missouri Head Injury Advisory Council recognizes that the course of rehabilitation will vary according to the patient's needs and the availability of services. Part of the challenge of providing adequate care for persons who sustain traumatic head injury is the diversity of needs after injury. Post-injury needs can range from full time care to community re-integration. The order in which services are used can also vary; some people will move from acute medical care into community integration while others may require extended periods of nursing care. Thus, services must be flexible, but also allow for the most frequent progressions.

The service delivery system envisioned by the council is flexible. Rehabilitation of persons who have sustained traumatic head injury is based upon small steps emphasizing increased demands until the person's maximum level of independence is established. While returning to the community living is the ultimate goal, however, it must be recognized that the level of functioning will vary and survivors of head injury may require differing support services.

Some of these services are in place and are provided by some state and local agencies. There are very few services and programs following acute or post acute (functional living) rehabilitation for persons who require long-term care or support. Some of the services needed (i.e. case management, and housing) are available to other disability groups, but are not available specifically for persons with a head injury. No state to date has developed a comprehensive statewide service delivery system addressing all the components for persons with head injuries and their families.

With regard to state services in Missouri it has been difficult for persons with head injuries to obtain long-term care and community support services from various state agencies due to eligibility requirements, availability of funding, and availability of services experienced in providing services to persons with head injury. Those persons who do have insurance or another third-party payer often find that their third-party coverage does not apply for long-term rehabilitation, long-term care and/or community support services. Yet, there is no state agency with specific responsibility for developing and providing those needed services or coordinating services through a case management system.

Planning

The Missouri Head Injury Advisory Council meets one the federal Task Force recommendations to establish interagency coordination at the state level. Established in 1985 under Executive Order and by legislation in 1986, the council is comprised of consumers, family members, state legislators, professionals, and state agency heads vocational rehabilitation, special education, mental health, health, medical services, insurance, vocational education, and public safety.

The council through its committees and task forces, studies and makes recommendations for improving, coordinating, and establishing services for individuals with traumatic head injury and their families.

The approach undertaken by the council in planning a comprehensive service delivery system is as follows:

•Define/identify individuals with head injury who may need services

•Define/assess head injury services needed

•Identify gaps in current state service system

•Expand and coordinate existing state and private services

•Develop distinct services not otherwise provided by existing state or private agencies

Missouri Data Systems

The following are state computerized data systems which may be useful in planning for a service system.

Missouri Department of Health

•Missouri Head and Spinal Cord Injury/Trauma Registry—All hospitals are mandated to report by state law.

•Death Certificate System—The department has added a code to determine if death resulted from a head injury.

•Hospital Discharge Data—The data set includes ICD-9 Codes.

•Annual Nursing Home Survey—All nursing homes are surveyed annually by way of a questionnaire. The self-questionnaire contains a question with regard to the number of residents with head injury.

•Special Health Care Needs Program —The reporting system includes ICD-9 codes.

Missouri Department of Mental Health

•Division of Mental Retardation and Developmental Disabilities:

All clients receive a DSM III-R diagnosis (client intake system), however, for the most part, mental retardation diagnoses from the DSM III-R are used. The division does not track head injury as a separate category.

To assist with program planning and development the council first defined head injury and services which may be needed. The definition for traumatic head injury was included in the legislation establishing the head and spinal cord injury registry. The definition is also used for request for proposals for head injury services issued by the Missouri Division of Purchasing for the Office of Administration, Division of General Services.

Also during 1986, the council identified and defined services and programs which may be needed. The report, *Proposed Service Delivery System for Rehabilitation of Missourians with Head Injury* was distributed statewide for comment. Starting in FY'88 these definitions were incorporated in the Request for Proposals for head injury services.

•Division of Comprehensive Psychiatric Services:

Client intake file for all clients and diagnosis is referenced by DSM III-R code. As there is not a specific code for head injury, diagnosis would probably be an Axis 3 (medical) Organic Mental Disorder which includes brain injury, tumor, disease, infection. The division would need to look at patient/client medical history to determine head injury.

Missouri Department of Elementary and Secondary Education

•Division of Vocational Rehabilitation:

A client intake file includes a code for head injury. The disability code is taken from the clients' medical reports.

•Division of Special Education:

New federal requirements to require reporting children with head injury starting Fiscal Year 1993.

Missouri Department of Social Services

•Medicaid Claims are computerized and show ICD-9 Codes.

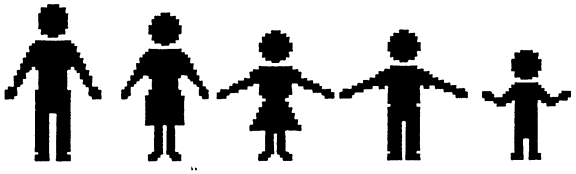
ICD-9=International Classification of Diseases, 9th Revision

DSM III-R=Diagnostic and Statistical Mannual of Mental Disorders, Third Edition Revised

Incidence and Prevalence of Head Injury

Determining the incidence and/or prevalence of head injury in Missouri has been a priority for the Missouri Head Injury Advisory Council. In order to plan for services, the council needs to know not only the type of services, but how many people will need the various programs. From the time the council was created this information has been difficult to determine due in part, to the (1) lack of prevalence studies and (2) omission of head injury in reporting systems.

To address this problem the council initiated two projects. The first project of the council was to initiate legislation mandating hospitals to report head injuries to the Missouri Department of Health, Division of Health Resources, the agency responsible for gathering and managing various public health statistics. The legislation was introduced and passed in 1986 and requires the reporting of head and spinal cord injuries to the department. The Division of Health Resources implemented the head and spinal cord injury registry July 1, 1987, and has analyzed the data obtained during the 1988 calendar year. Some of the data is contained in this report.



The second project initiated was a statewide random telephone poll to determine: (1) how knowledgeable are Missourians with regard to head injury and (2) how prevalent is head injury in Missouri.

Incidence

In the past, the council has relied on national statistics to project how many head injuries occur each year. Through the Missouri Head and Spinal Cord Injury Registry, Missouri now has its own statistics on the number of head injuries each year.

Missouri Head and Spinal Cord Injury/ Trauma Registry

The Department of Health has released figures regarding the data received during the first and second calendar year since implementation of the registry. In general, the 1989 results are very similar to those for 1988. The department is still correcting errors in a few of the records, so the results being reported are not final.

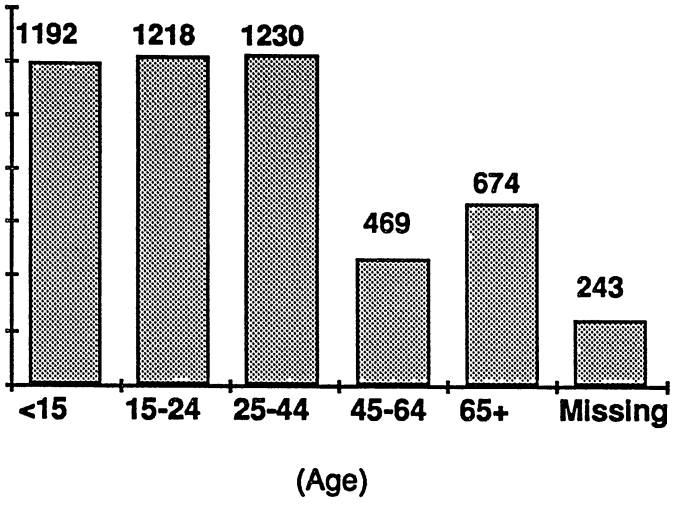
The department has grouped head and spinal cord injuries into three group—(1) head injuries, (2) spinal cord injuries, which excludes diagnosis code 805, fracture of the column without mention of the cord, (3) and all head and cord or column injuries. Individuals who die in the emergency room are not admissions to the hospital, and they are excluded from the Discharge Disposition table. Similarly, emergency room deaths and deaths after admission have been excluded from the Disability at Discharge table.

	1988	1989
Head Injury	5,078	5,026
Spinal Cord Injury (exluding 805, ICD-9 Code)	264	268

Three out of four head and spinal cord injury records (76%) were for head injury. The rate for males was nearly twice that for females. The 15-24 age group had the highest head injury rate and accounted for 25 percent of the head injuries. The rate for minorities was 50 percent higher than that for whites (27% higher in 1988). The rate per 100,000 for black and other minorities was 139.3 compared to 92.4 per 100,000 injuries who were white.

Age

The 1989 registry data shows that head and spinal cord injuries are overrepresented primarily among 15-24 year old individuals, and to a lesser extent, young children and older adults. This overrepresentation is directly related to the causes of the injuries.



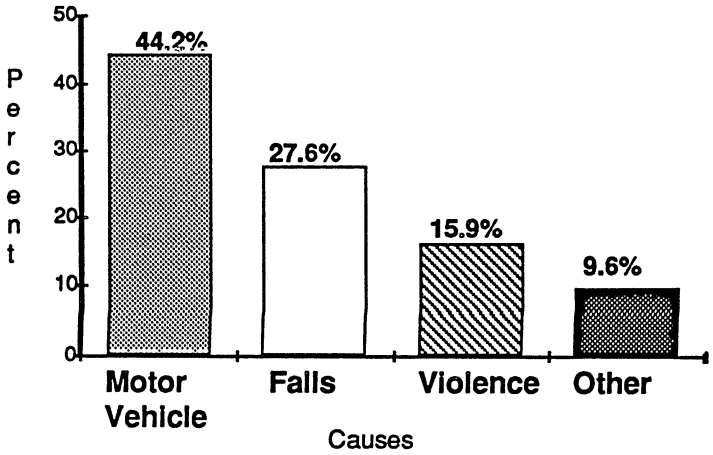
Rate per 100 thousand	
∠15 years of age	108.8
15-24 years of age	164.9
25-44 years of age	76.4
65+ years of age	93.7

Data from the Missouri Head and Spinal Cord Injury/ Trauma Registry shows that head injuries are over-represented among 15-44 year old individuals.

Causes

Motor vehicle crashes accounted for nearly one in two head injuries (45%) and falls accounted for about one in four (28%). Motor vehicles accounted for one out of two spinal cord injuries (53%) and falls accounted for one out of five spinal cord injuries (22%).

According to the 1988 registry data, there are two predominate geographic clusters of motor vehicle head injuries in the state. One cluster is formed by the counties in central and eastern Missouri. The Department of Health explains that this cluster is likely due to two separate phenomena. Most of the counties surrounding the St. Louis metropolitan area have high motor vehicle head and spinal cord injury rates. This is one of the fastest growing areas of the state, as people are choosing to live in the suburban fringe rather than in St. Louis City or County. However, even after adjusting for the high



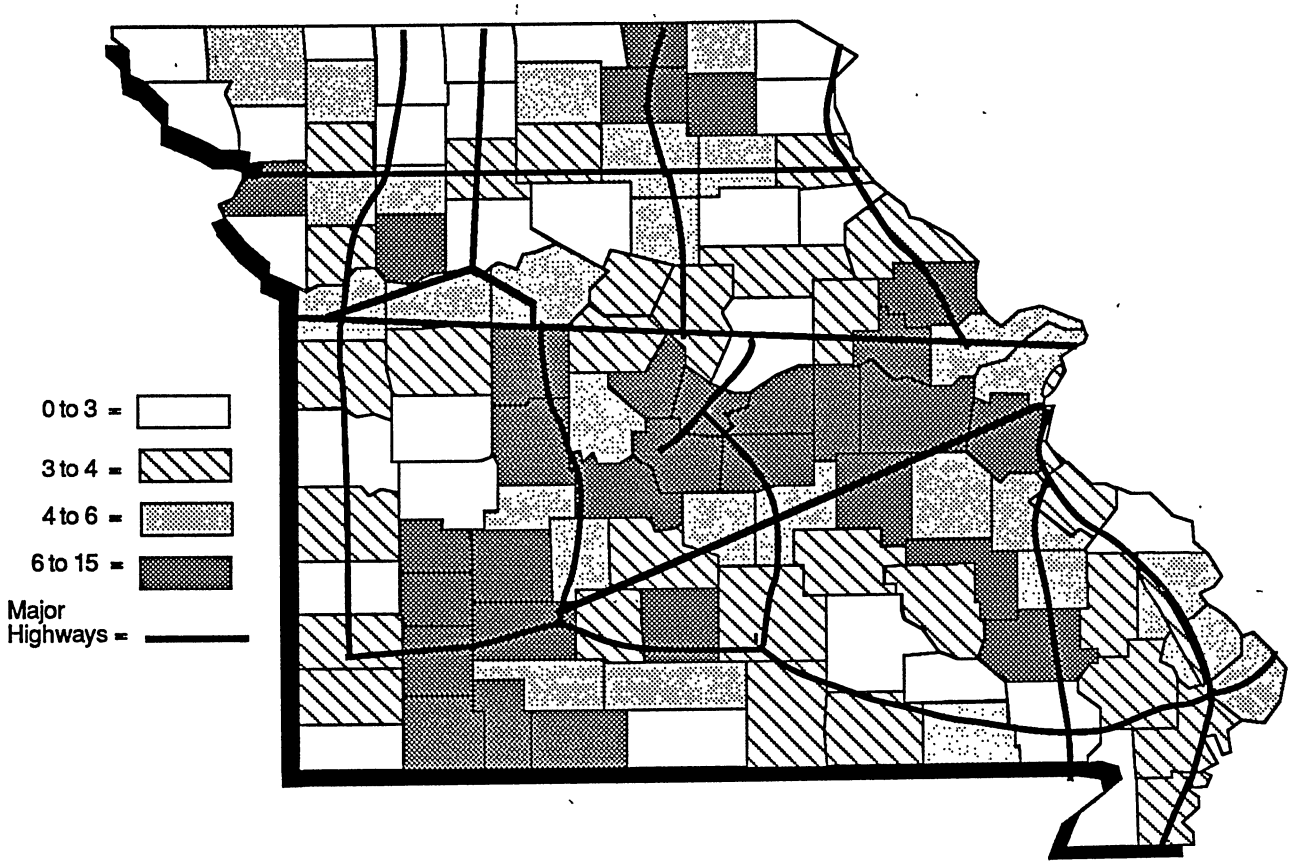
commuter mileage in these areas, there is an excess of head and spinal cord injuries in the St. Louis suburban fringe counties.

The group of counties with high injury rates in Central Missouri represents the second phenomenon: high injury rates in retirement and tourist areas close to the Ozark and Truman lakes in Central Missouri.

The second cluster of injury rates, located in Southwestern Missouri, also appears to be related to the tourist and retirement community. These counties include tourist attractions and retirement areas associated with Pomme de Terre, Stockton, Table Rock, and Taneycomo Lakes. These are among the fastest growing areas of the state.

There tend to be lower rates of motor vehicle-related head injuries on dual lane roads where travel is presumably safer. Generally, the injury rates are lower for the counties along the interstates from Kansas City to St. Louis, Omaha, Des Moines, and Joplin. The counties along the interstate from, St. Louis to Cape Girardeau also have lower injury rates.

Rate of Injuries Caused by Motor Vehicles
Per Hundred Million Miles
1988

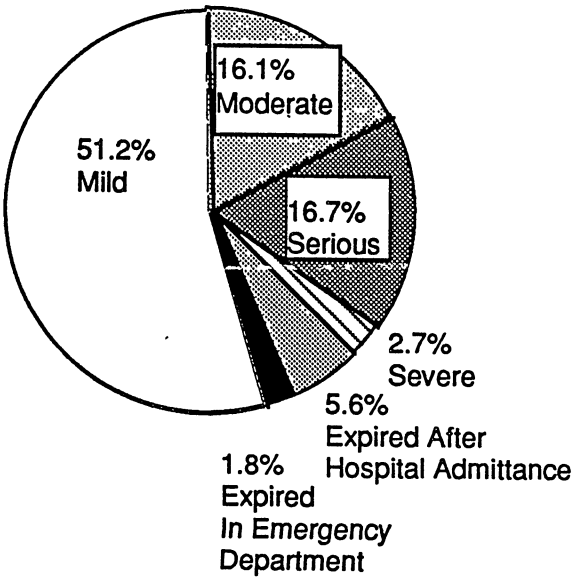


Disability/Deaths

Almost one in three (29%) of the head injuries reported resulted in a serious, severe, or fatal injury. About one in twelve (8%) died in the emergency room or after admission. There are few other medical conditions that have such a high immediate fatality rate. One in 25 (4%) was discharged with a major disability.

Glasgow Coma Scale
(on arrival to emergency department)

Score	Number	Rate per 100k population
0-5	346	6.7
6-8	229	4.4
9-12	377	7.3
13-15	2297	44.5
Missing	1777	- - -



Discharge Summary

The majority (73.4 %) of persons with head injury were discharged to home. Around six percent (6.1) were discharged to a rehabilitation facility. Approximately three percent were discharged to another hospital and another three percent were discharged to a nursing home.

Discharge Disposition

Home	3789	73.4%
Rehab Facility	315	6.1
Home, Rehab	37	0.7
Other Hospital	162	3.1
Nursing Home	180	3.5
Home Health	81	1.6
Other	73	1.4
Expired after Admission	290	5.6
Missing	49	- - -

Disability at Discharge

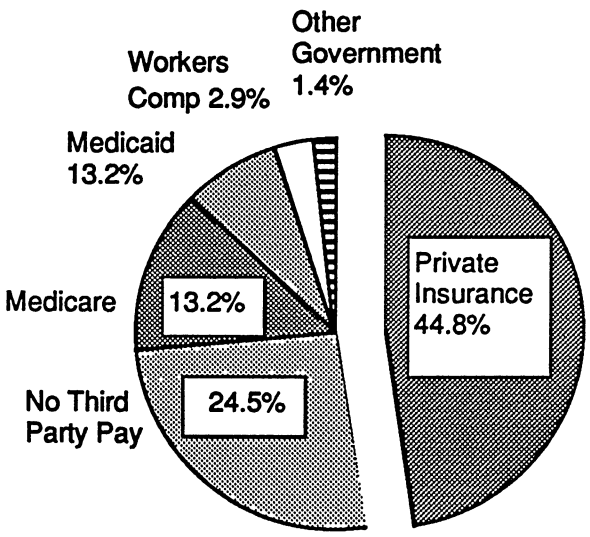
Major	169	3.3%
Moderate	350	6.8
Minor	1207	23.4
None	2191	42.5
Missing	720	- - -

Note: The scoring is based on degree of independence in three areas: feeding, locomotion, and expression. The users of the data are aware that deficits relating to cognition, memory, behavior, and in other areas may not be acknowledged until after discharge from a hospital.

Average length of stay in the hospital for a person with a head injury was 6.6 days. For a person with a spinal cord injury the average length of stay was 19.4 days.

One in two individuals with head injury had government insurance or no insurance (49%).

Source of Payment



Reported by the Missouri Department of Health from data from the Missouri Head and Spinal Cord Injury/Trauma Registry.

Prevalence

Statewide Head Injury Poll

By way of a contract with the University of Missouri Media Research, a total of 1,123 Missouri residents, 18 years of age or older, were interviewed by telephone between July 11 and August 11, 1988. The state was divided into seven regions which geographically represented the entire state.

The head injury survey questions pertained to three general areas: (1) Generally knowledge about head injury, its causes, and resulting problems; (2) extent of head injury, problems associated with head injury, services received, and services needed, and (3) demographics. With regard to prevalence persons interviewed were asked:

• Have you personally had a blow to the head which affected your ability to perform routine activities or work?

•Has any member of your immediate family had a blow to the head which affected his/her ability to perform routine activities or work?

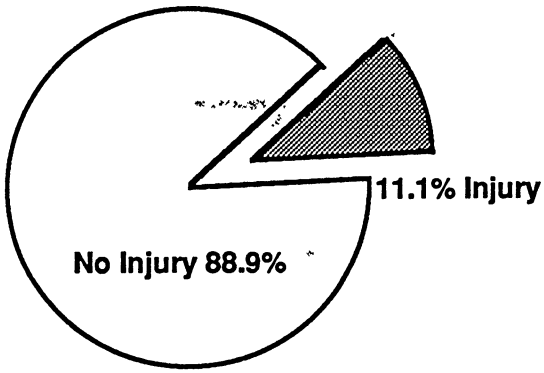
•Do you personally know any Missouri residents who, within the last ten years, has had a blow to the head which affected his or her ability to perform routine activities or work?

Personally Experienced a Head Injury

Eleven percent of those surveyed (125 persons) said they had personally experienced a head injury. Of these, 62 percent were injured seriously enough to lose consciousness. Most lost consciousness for only a few minutes, but 17 percent were unconscious for one to three hours, 7 percent were unconscious for four to 24 hours, while 5 percent were unconscious for an extended period of time.

Age at the Time of Injury

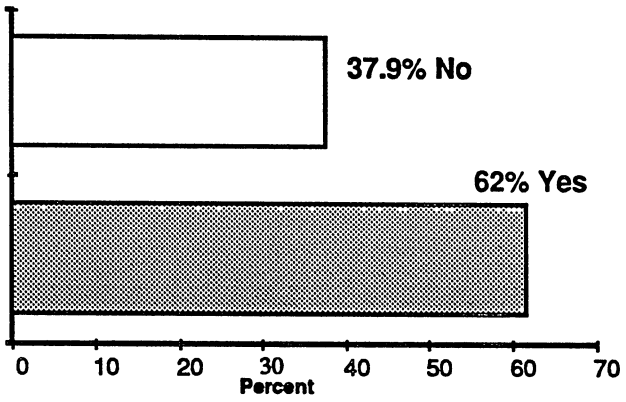
Eighty percent were below the age of 35 when they were injured. In fact, 23 percent were 12 or below and 22 percent were between 13 and 17. Sixteen percent were between 18 and 24, and 19 percent were 25 to 34.



When asked, "Have you personally had a blow tothe head which affected your ability to perform routine activities or work?", 11.1% answered yes.

Problems Associated with Head Injury

Seventy-six percent of those injured said they experienced headaches, and almost 57 percent said they developed problems with movement or balance. Twelve percent said they developed speech problems, and 10 percent said they experienced behavioral problems. Thirteen percent said they underwent personality changes, and 11 percent experienced impulsiveness. Fifteen percent of those injured said they had been unable to work or go to school continuously for more than six months since their injury.



Cause of Injuries

About 5 percent of those suffering injuries said they were involved in a car crash, while 3 percent had a fall. Slightly more than 1 percent received an industrial related injury. Others were injured by being hit or abused, while on a motorcycle or three-wheeler, while playing sports, while riding a bicycle or received some type of injury at home or school. All of those who said their injuries were the result of being hit or abused were below the age of 34.

When those who had experienced a head injury were asked if they were unconscious, 62 percent answered yes. Most (71%) lost consciousness for only a few minutes, but 17 percent were unconscious for one to three hours. Seven percent were unconscious for up to 24 hours and five percent were unconscious for an extended period of time.

Family Member with a Head Injury

Almost 12 percent of those interviewed said that a member of his immediate family had received a head injury. Of those injured, 75 percent were male household members. Forty-six percent said that his son had been the person injured, while less than 10 percent said his daughter had been injured.

Sixty-eight percent said the injured family member had lost consciousness. Most were unconscious for longer periods of time than those who said they themselves had received a head injury.

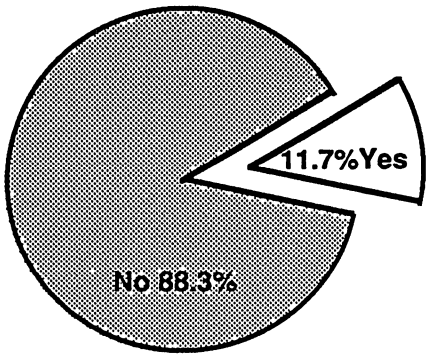
Almost 26 percent said the family member had not been able to work or go to school continuously for six months since the injury. Fourteen percent were unable to function on their own.

Services Required

Eighty-eight percent required the care of a physician, and 71 percent required hospitalization. Twenty-seven percent needed rehabilitation, and 15 percent said the family member required psychiatric care or counseling. Seven percent said the family member needed job training, while 8 percent said the family member needed nursing home care. Nearly 10 percent reported that the family member's medical costs were $50,000 or more.

Cause of Injury

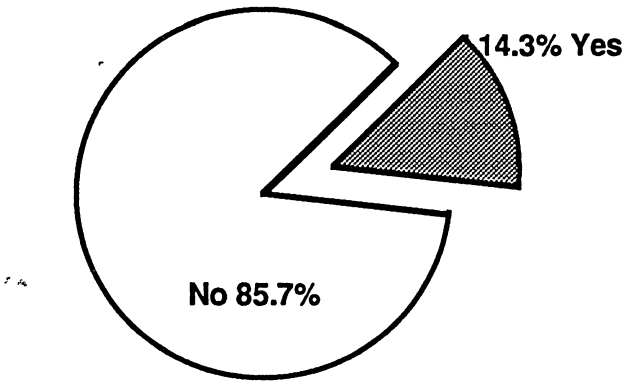
Five percent were injured in a car crash and 4 percent were injured in a fall. A few were motorcycle, three-wheeler injuries, diving or swimming injuries, industrial or sports related injuries. Some were hit or abused or were shot.



When asked, "has any member of your immediate family had a blow to the head which affected his/her ability to perform routine activities or work?", almost 12 percent answered yes.

Knows Someone with a Head Injury

Fourteen percent of those surveyed (160 persons) said they knew at least one person who had received a head injury. Sixty-three percent could recall one victim, while 20 percent could recall two, 9 percent could recall three and 4 percent could recall four. Four percent knew five or more persons. Of those who knew a person with a head injury, 81



percent said the person was a male.

Problems Associated with Head Injury

Those interviewed reported a variety of effects as a result of the injury to their friends or acquaintances. Sixty-five percent said the person with the head injury had problems with movement or balance, 64 percent mentioned memory loss and 52 percent mentioned headaches. Forty-six percent reported speech problems, 15 percent developed seizures. Thirty-four percent said the person experienced personality changes, 32 percent became impulsive and 30 percent developed behavior problems according to those interviewed.

Seven percent said the person(s) they knew was injured in a car accident. About 2 percent said the victim fell. A few were hit or abused, were injured in a motorcycle, three wheeler or bicycle accident, were injured while swimming or diving or were shot. Sports injuries, use of drugs or alcohol, industrial accidents and other types of accidents were mentioned.

Summary

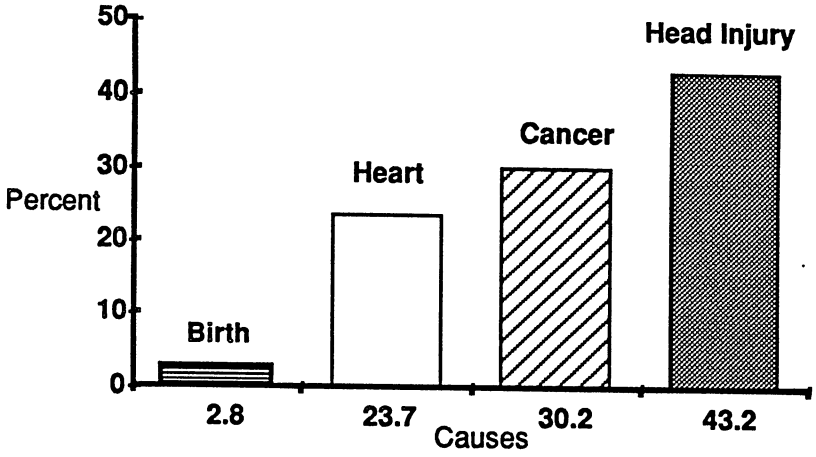
Both the survey and the register indicate that head injuries are a serious public health problem in terms of number of cases, number of severely disabled persons, and number of deaths. The fact they they occur primarily among young people makes the problem even more alarming. At the very least, those receiving head injuries reported experience headaches. Others are left with severe disabilities

that render them incapable of working or even getting along with other people. Those most at risk for head injuries are children and young adults. Males are more at risk than females. This is most likely the result of lifestyles among young males. A second group at risk appears to be the elderly, who are more likely to be injured in a fall.

Public Knowledge of Head Injury

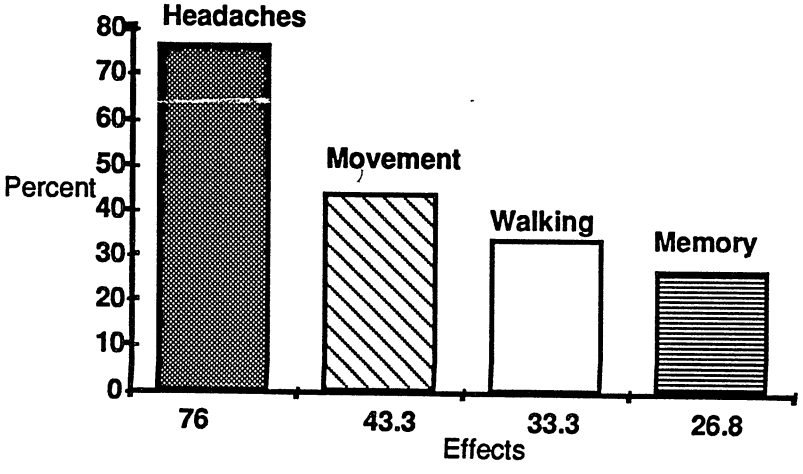
Forty-three percent of those interviewed said they thought injuries were the leading causes of death and disability among Missourians. Thirty percent thought cancer was the leading cause, while 24 percent thought heart disease was the leading cause. Less than 3 percent thought birth defects were major causes. Seventy percent said they heard a doctor or someone else use the term, "head injury."

Perceived As Leading Cause of Disability



Forty-two percent considered head injuries to be a very serious health problem, while 45 percent considered it a somewhat serious health problem. Seventy-five percent said car accidents most often accounted for head injuries suffered by those living in Missouri. Falling was considered a major cause by 25 percent. Motorcycle or three-wheeler accidents were mentioned by 11 percent. Almost 4 percent mentioned hitting or abuse as a cause.

Perceived Major Effects of Head Injury



Those interviewed were asked what types of problems they thought a person would have as a result of a head injury. Thirty-two percent mentioned paralysis, 29 percent mentioned memory loss, 16 percent mentioned thinking problems and 12 percent mentioned problems with walking. Also mentioned were speech and learning problems and trouble with getting along with other people. A variety of problems were mentioned by a few of those surveyed. These included: eye problems or blindness, blood cots, fever, depression, brain damage, dizziness, headaches, cancer, epilepsy, deafness, coma and back pain.

Prevention

The National Head Injury Foundation has coined the slogan, "The only cure for head injury is prevention," as the incidence and severity of head injury can be reduced through prevention and early intervention activities. Motor vehicle related crashes, bicycles, motorcycles, and off-road vehicles accounted for over half of all head injuries in Missouri in 1988 and nearly half in 1989. Falls accounted for one in four injuries in 1989 and are the second leading cause. In 1988, thirty-seven percent of injuries caused by falls occurred among persons age 65+ and another 28 percent of injuries due to falls occurred among children less than age 15. Diving injuries, industrial injuries, assaults, weapons and recreational injuries also result in head injuries.

Injury has traditionally been regarded primarily as an unavoidable accident rather than a public health problem. However, injuries can be prevented with a variety of strategies. Three general strategies are available to prevent injuries: (1) *Persuade* persons at risk to alter their behavior, (2) *require* individual behavior change by law or administrative rule and (3) *provide* automatic protection by product and environment design.

In 1983, Congress enacted a law authorizing the secretary of the Department of Transportation to request a study on trauma injury by the National Academy of Sciences. The committee issued the report *Injury in America: A Continuing Health Problem* in 1985. One of the findings of the committee was the lack of the data necessary to allow for the study of the epidemiology of most injuries. The committee believed that systematic data collection is essential for planning and evaluating prevention programs.

In 1988, the U.S. House Committee on Appropriations encouraged the establishment of an Interagency Head Injury Task Force to identify the gaps in research, training and service delivery and recommend solutions in meeting the needs of persons with traumatic head injury. The Task Force released its report spring of 1989. In the report the Task Force made five recommendations with regard to primary prevention:

1.) Developing behavioral and environmental interventions aimed at reducing the frequency or severity of traumatic brain injury.

2.) Encouraging the use of both innovative and proven model prevention programs with provisions to evaluate their results.

3.) Encouraging activities that minimize head injury risk in athletics and stimulate the use of helmets (or other protective device) by boxers, bicyclists, motorcyclists, and other high-risk groups.

4.) Evaluating existing societal barriers to the effective implementation of prevention of strategies.

5.) Improving community-level access to existing database systems to assist in designing and developing prevention programs.

To address the magnitude of the problem of injuries nationally a Center for Injury Control has been established in the organizational structure of the Centers for Disease Control. Several grants has been let across the nation to conduct injury research, to establish state injury surveillance systems, and to assist states in developing injury prevention programs.

The Current Service System: Prevention

Head Injury Registry

The Missouri Department of Health implemented the head and spinal cord injury registry July 1, 1987, as the result of legislation which passed during the 1986 legislative session requiring all hospitals to report all head and spinal cord injuries to the department. That information will allow the state to be in a position to study and address the extent of injury in Missouri and the effectiveness of laws and educational programs directed toward the prevention of injuries.

Missouri is unique in that the state has five data systems which other states do not have: Missouri Head and Spinal Cord Injury Registry, Statewide Trafficway Accident Reporting System (STARS), Missouri Ambulance Reporting System (MARS), Hospital Admissions System, and the Death Certificates System. Four of these systems are administered by the Department of Health. The fifth system, STARS, is administered by the Missouri State Highway Patrol.

Planning

The Missouri Department of Health, Division of Health Resources, received a capacity development grant September 1989, from Centers for Disease Control. The four year grant established a state injury prevention section within the division. The section will coordinate prevention programs, evaluate prevention efforts, and coordinate state policy with regard to injury prevention. An advisory committee was appointed by the director of the Department of Health. Four working committees have been formed addressing trafficway injuries, falls and unintentional injuries, intentional injuries, and occupational safety and health.

State Laws

Missouri has several laws designed to reduce fatalities and injuries including: mandatory seat belt law for occupants in the front seat of automobiles, child safety restraints for children under the age of four, motorcycle helmet usage law for all riders,and severe penalties for DWI (Drinking While Intoxicated). In addition, Missouri has passed legislation requiring all ATV (all terrain vehicle) drivers under the age of 18 to wear a helmet and persons under the age of 16 must be supervised by an adult.

Public Education/Prevention Programs

The Missouri Head and Spinal Cord Injury Prevention Project, University of Missouri-Columbia, conducts school assemblies addressing the need for exercising good judgment in order to avoid unnecessary accidents. The Project assisted in the making a nationally acclaimed, award winning film called *Harm's Way* featuring young adults from Missouri with head and spinal cord injuries. The prevention program has been modeled in various parts of the state, as well as nationally. The Council has supported expanding the program statewide and has supported the program in its efforts to evaluate the effectiveness of the program. The program receives financial assistance from the Missouri Department of Health, Missouri Division of Highway Safety, the Missouri Safety Belt Coalition and other sources.

The SAFE KIDS program, a national coalition of 65 civic and health organizations was formed to focus on childhood injury. Initiated by Children's Hospital National Medical Center, Washington, D.C., the campaign is supported by Johnson & Johnson and the National Safety Council. During the past year, the program focused on bicycle safety. In Missouri, there is a statewide coalition and several local SAFE KIDS Campaigns. Cities which have coalitions include Columbia, Kansas City, St. Louis and Springfield.

The National Head Injury Foundation has joined with the American Academy of Pediatrics and the Bicycle Federation of America to launch Head Smart, a national campaign to prevent head injuries through increased use of approved bicycle helmets. Material to promote local awareness is available through the Foundation and its state chapter, the Missouri Head Injury Association.

The Children's Trust Fund, funded through donations, is the principal funder of child abuse prevention programs and planned to spend between $500,000 to $600,000 in Fiscal Year 1990. Statewide about $70 million was proposed to be spent by the Missouri Department of Social Services for children's protective services and the investigation and treatment of child abuse. Of that, $25 million was targeted for foster and residential care.

Other educational efforts regarding safety are conducted statewide and locally by or with support from the Missouri State Highway Patrol, the Missouri Safety Belt Coalition, Missouri Safety Council, and the Missouri Division of Highway Safety.

Emergency Medical & Medical Services

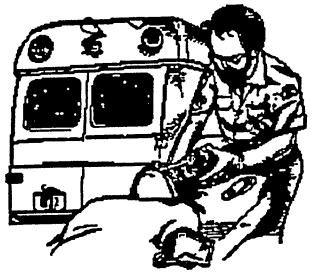
The outcome of injury depends not only on its severity, but also on the speed and appropriateness of treatment. Rehabilitation should first begin with the emergency medical services team at the scene of the injury. Proper attention should be provided in order to prevent further injury. Trained paramedics are able to attend to airways, treat shock, and monitor a patient's condition. They can also notify the receiving hospital regarding the patient's condition and the estimated time of arrival.

The emergency medical services system has improved over the years. Much of the improvements have been attributed to the military which has used triage methods at the scene of the accident and helicopters to transport severely injured patients to receive care in a minimum amount of time during military conflicts. "Communication systems are needed to facilitate decision making, injury management at the site, and the rapid delivery of the patient to a hospital that can provide the needed care," according to the report, *Injury in America: A Continuing Health Problem.*

The Federal Interagency Task Force also recommends: (1) Enhancing the provision of emergency services through training, improved communications and availability of rapid transportation of the injured and (2) ensuring adequate geographical distribution of local acute care trauma facilities.

After the victim is attended to at the site of the injury, he or she is usually, then, transported to the hospital emergency department where the medical team tries to stabilize the patient as well as to diagnose the immediate problems. For more than a decade the American College of Surgeons has pushed for a regional system of hospital-based trauma centers. A trauma center is a hospital where the medical staff has made a commitment to provide 24-hour "in-house" coverage by surgeons, anethesiologist and supporting staff to care for trauma patients.

Many patients with "minor" head injury may be discharged from the emergency department. (Such patients, however, may later experience problems such as headaches, memory disturbances, confusion and disorientation.) For others who may be more severely injured, surgery may be performed for various reasons. After surgery, the patient may be moved to the intensive care unit for acute care until he or she no longer needs acute monitoring.



If the patient is comatose, he or she may be provided stimulation and physical therapy to prevent deformity or atrophy of the bones and muscles. If the patient appears to be in a persistent vegetative state, or emerging from coma, the hospital may discharge the patient to a nursing facility, long-term rehabilitation program or to home for the family to provide or arrange for nursing care.

Current Service System: Emergency Medical & Medical Services

Trauma Centers

Until legislation passed during the 1987 session, Missouri's trauma center system was voluntary on the part of the hospitals. The Missouri Department of Health developed Trauma Triage Protocol to assist emergency department personnel in the treatment of trauma patients. Like the trauma center program, this protocol was voluntary. The legislation which established a trauma center system required the department to develop criteria for a trauma center and to designate trauma centers after on site review. The legislation also required licensure of air ambulances and required all ambulances to transport seriously injured patients to the closest designated trauma center or hospital according to protocol developed by the department.

The legislation established the State Emergency Medical Services Council statutorily which is to assist the department with developing rules and

regulations necessary to implement the new requirements and to continue to develop recommendations for improving the emergency medical services system.

The Division of Health Resources with input from the State Emergency Medical Services Council drafted regulations regarding criteria for trauma center designation and the rules and regulations are in the process of being reviewed. Trauma centers have been reviewed and designated across the state.

The head and spinal cord injury registry data not only collects data with regard to the number of injuries, but also with regard to method of transportation, length of time in the emergency department, medical treatment provided, disposition of the patient and so forth. Through data collected from the registry, the Department of Health is able to provide hospitals a report listing specific cases identified by audit filters that hospital quality assurance committees may want to review and to take action in order to remediate any potential problem in the emergency and medical care service delivery system.

The Department of Health, Division of Health Resources, through its Bureau of Emergency Medical Services administers the State Ambulance Licensure Law. Its programs includes: (1) Review and approval of curricula at training facilities that offer courses for emergency medical technicians (EMT), mobile emergency medical technicians (MEMT), emergency medical technician paramedics (EMT-P), first responder and corresponding refreshers courses; (2) develop and administer uniform EMT and MEMT certification tests; and (3) develop and coordinate a statewide EMS communications systems.

The statewide emergency medical communications systems includes 141 hospitals with two-way radio capabilities for communicating with ambulances. This system enables an ambulance attendant to radio a hospital to receive advice from a physician or other emergency department personnel concerning care of an emergency patient that the ambulance transporting.

Rehabilitation

Rehabilitation refers to a comprehensive series of interventions for physical, medical, cognitive, psychological disabilities designed to restore a person to his or her maximum functional potential. This process should begin immediately after the injury as possible. Some general hospitals maintain a rehabilitation unit where physical, speech and occupational therapies are provided. As the patient progresses medically, he may receive such therapies and may be moved to a rehabilitation unit or a separate short-term rehabilitation hospital which, in addition, may also provide cognitive rehabilitation.

The patient may be evaluated by a team of professionals, including a neuropsychologist or psychologist, which, then, develops a rehabilitation program to address the patient's problems. These problems may be related to memory, attention, movement, balance, personality changes, difficulty with complex thinking and with judgment, inappropriate behavior, and difficulty with speech and language. Patients are usually discharged after reaching a plateau of recovery, although many may still require continued rehabilitation beyond the acute stage.

The Federal Interagency Task Force recommendations with regard to rehabilitation are:

1.) Encouraging the continuing review of standards of service for traumatic brain injury clinical care and rehabilitation by appropriate public and private organizations.

2.) Emphasizing outpatient rather than inpatient services for noncritical care and rely on outpatient services at the local level.

3.) Focusing on the ultimate goal of independent function in the community, including training in problem solving and incorporating proven behavior and educational therapies.

4.) Encouraging appropriate local and state agencies to mount special efforts to provide counseling for survivors of traumatic brain injury and their families; supportive resources such as day care; traumatic brain injury vocational counseling and training; and specialized treatment in the case of the traumatic brain injured with mental health, alcohol, and substance abuse problems.

5.) Utilizing for traumatic brain injury care appropriate mental health, mental retardation and special education facilities and programs.

6.) Facilitating community reentry by the provision of transitional and supervised residential facilities and programs. For those survivors whose recovery is delayed or incomplete, a wide range of residential settings is needed, from skilled nursing units to domiciliaries and semi-independent group living facilities.

The Missouri Head Injury Advisory Council has defined three types of rehabilitation programs: (1) *Acute Brain Injury Rehabilitation,* (2) *Functional Living Rehabilitation* and (3) *Transitional Living Rehabilitation.* Most often, after traumatic head injury, the patient goes from acute medical care to *acute rehabilitation* which focuses on physical and gross cognitive deficits. The program is designed to prevent and/or minimize chronic disabilities while restoring the individual to the optimal level of physical, cognitive and behavioral functioning. The rehabilitation program should be carefully coordinated and implemented as soon after onset of injury as is medically feasible.

Functional Living Rehabilitation Programs provide intensive rehabilitation with goal directed services to persons who have either completed acute rehabilitation or who have no major acute rehabilitation needs. Emphasis in this program is on functional cognitive, memory, or perceptual deficits, and appropriate interpersonal skills. Services may be delivered on an inpatient (residential) or outpatient (day program) basis.

Transitional Living Rehabilitation Programs provide intensive rehabilitation with goal directed services to persons who have sustained traumatic brain injury and who have completed acute and functional living rehabilitation programs or who have no significant need for such services prior to transitional living programs. In these programs, participants would typically move from close observation and supervision to independent living with minimal supervision. Transitional living programs may exist independently or may be part of a larger program. The program should provide safe, accessible housing which allows transition from group living situations to independent living. Housing facilities should include provision for 24-hour supervision.

The goal of rehabilitation is to enable a survivor of head injury to return to his/her employment/school and to his or her home environment. Many will return to work provided that certain modifications in the work environment take place which will enable the person to return to his or her job. Others will require extensive rehabilitation or programs which specialize in pre-vocational or vocational rehabilitation in order to be able to engage in competitive employment. For those who will not be able to engage in competitive employment without some type of assistance, other alternatives will need to be available.

Pre-vocational/Pre-employment Training readies a person for vocational rehabilitation. The program addresses behavioral and/or cognitive compensation strategies learned through cognitive rehabilitation and/or work adjustment training. This type of program often fills a gap between functional/transitional rehabilitation and vocational rehabilitation services provided by the Missouri Division of Vocational Rehabilitation.

Vocational Rehabilitation readies a person for employment. The federal Rehabilitation Act of 1975 as amended is administered through the Missouri Department of Elementary and Secondary Education, Division of Vocational Rehabilitation. Vocational Rehabilitation is a program designed to help physically or mentally disabled persons become employable. Many services are provided under the federal program of which some are free and others assessed by the ability to pay. Some of the services made available to clients are as follows:

1.) A doctor's examination to assess the severity of the disability.
2.) Medical and hospital care to reduce the disability and improve changes for employment.
3.) The purchase of such items as artificial arms

and legs, braces, wheelchairs or hearing aids to increase the ability to work.

4.) Job training. This may include college education, commercial or trade school, or on-the-job training.
5.) Work evaluation and adjustment.
6.) Transportation allowance while receiving medical treatment or job training arranged by the vocational rehabilitation counselor.
7.) An allowance sufficient for noon meals if job training is provided in the client's home community.
8.) The cost of room and board if job training is provided in the client's home community.
9.) Equipment needed for employment (including tools and a license if needed).
10.) Help in finding a job.
11.) Help in solving problems encountered on the job.

To be eligible for services through the Division of Vocational Rehabilitation a person must meet the following requirements:

1.) The presence of a physical or mental disability which for the individual constitutes or results in a substantial handicap to employment and

2.) A reasonable expectation that vocational rehabilitation services may benefit the individual in terms of employability.

The Current Service System: Rehabilitation

Acute, Functional and Transitional Rehabilitation

Rehabilitation programs for survivors of head injury are relatively new. Most of the programs providing services are private facilities. Several hospitals provide acute rehabilitation and outpatient rehabilitation services such as speech therapy, physical therapy and occupational therapy on a limited basis. A few hospitals and rehabilitation facilities provide functional living rehabilitation services. Most of the programs require the patient or client to have the ability to pay for services or have access to third party pay such as insurance or worker's compensation. For those who do not have the ability to pay, the financial resources are limited.

The Missouri Medicaid program provides very little reimbursement for outpatient therapy services. However, legislation passed during the 1988 session which not only expanded Medicaid eligibility for children, but also expanded services to include comprehensive day rehabilitation, defined as post acute (functional living) rehabilitation for trauma patients. Provider enrollment in the program began in January 1990, with three providers initially participating in the program.

As the result of legislation passed during the 1985 session, the name of the State Chest Hospital was changed to the Missouri Rehabilitation Center. The facility, administered by the Missouri Department of Health, is located in Mt. Vernon. A head injury unit was established January 1986 from a state appropriation designated for that purpose. The Missouri Rehabilitation Center provides acute rehabilitation, functional living (residential) and transitional rehabilitation programs.

Also during the 1985 session, an appropriation ($500,000) was made to the Department of Health for purposes of purchasing services for survivors of head injury during FY'86. For FY'87 the program was reduced to $226,361. The department administered the program for two years, then requested that the appropriation be transferred to the Office of Administration, Division of General Services. The appropriation for contractual services for FY'88 was increased to $314,685. The same amount was appropriated for FY'89 and for FY'90 the Office of Administration, Division of General Services received an additional $207,000 for head injury services.

After the appropriation was transferred July 1, 1987, the Office of Administration extended contracts to Rusk Rehabilitation Center, Columbia, and Truman Medical Center-East, Kansas City, for functional rehabilitation services and both programs received a new contract for FY'89 and FY'90. Both programs provide services on an outpatient basis. Both Rusk Rehabilitation Center through its Brain Injury Rehabilitation Program and the Transitional Learning Center, Truman Medical Center-East serve eight clients on a daily basis.

Private programs which provide functional living rehabilitation services include Rebound, Inc., a health care corporation, located in Lee's Summit, and HEALTHSOUTH Rehabilitation Center, St. Louis, a publicly-traded corporation. Both of these programs offer other types of services for persons with

head injury. HEALTHSOUTH operates two facilities, one is an outpatient rehabilitation facility, and the other offers acute rehabilitation, transitional programming, respite care, coma management, and subacute rehabilitation.

SSM Rehabilitation Institute, a not-for-profit rehabilitation facility operating facilities in St. Louis and St. Charles, also offers functional living rehabilitation services. SSM has developed a pediatric program. Irene Walter Johnson operated by the Washington University Medical Center opened the Head Injury Resource Center in March 1986, offering functional living rehabilitation services. The Program has been transferred to St. John's Medical Center. These services are offered in an outpatient setting.

Rebound, Inc., broke ground in the spring of 1988 to construct a 40 bed transitional living center. The transitional program is designed for the higher functioning individual in preparation for community re-entry. Rebound accepts clients with the ability to pay or who have access to third party pay such as insurance or worker's compensation.

During March 1989, Bethesda General Hospital, St. Louis, announced a new head injury rehabilitation program offered in cooperation with Premiercare Rehabilitation Center, a Massachusetts based company specializing in the development and management of Neuro Rehabilitation Programs. The Premiercare Program provides intensive therapies in the areas of physical therapy, speech and language therapy, cognitive therapy and occupational therapy. The 28 bed dedicated unit has medical services provided by the Department of Neurology at St. Louis University School of Medicine.

Rehabilitation Network, St. Louis, offers outpatient therapies for persons with head injury. The services are provided in the home and a head injury program is available at the Network's facility. Several hospitals around the state offer varying types of services for persons with head injury.

Pre-Vocational & Vocational Rehabilitation

A day program was established in St. Louis by the Bi-State Chapter of the Missouri Head Injury Association with funding from the head injury state appropriation, presently being administered by the Missouri Office of Administration, Division of General Services, in FY'86. The program provides a variety of day program activities to ten persons three days a week.

Advent Enterprises, Inc., a not-for-profit corporation in Columbia, provides pre-vocational/employment training and is under contract with the Office of Administration, Division of General Services to provide services to approximately six persons at one given time. Blue Valley Head Injury Center, a not-for-profit organization, opened a program during the summer of 1988 designed to provide vocational training to assist clients to learn the work skills necessary to re-enter the community workforce. In the event community employment is not possible due to the severity of the client's deficits, the person can continue to work in the sheltered workshop environment. The program charges for services.

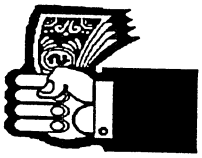
The Division of Vocational Rehabilitation has assigned a vocational rehabilitation counselor in each district office to work with clients with head injury. The division provides on going in-service training regarding head injury to its counselors to assist them in securing appropriate vocational services for survivors of head injury. The division purchases services for its clients from vendors rather than providing direct services.

The first vocational rehabilitation program recognized as expanding its services to head injured clients is Metropolitan Employment Services, St. Louis, with assistance from the division. The division also obtains vocational training services for clients with head injury from the following agencies: Advent Enterprises, Columbia; Goodwill Industries, St.Louis; Life Skills Foundation, St. Louis; and Rehabilitation Institute, Kansas City.

Through a cooperative effort involving Truman Medical Center-East and Rehabilitation Institute, both of Kansas City, and the Division of Vocational Rehabilitation, a job training program was developed for persons with head injury in the Kansas City area. Graduates of the Transitional Learning Center, Truman Medical Center-East, and other potential candidates for the job training program referred to the division for job placement are evaluated by the

Rehabilitation Institute. Those eligible are placed in temporary hospital jobs at Truman Medical Center. Job coaches are provided by Rehabilitation Institute with funding from the division. Job performance is monitored by the Transitional Learning Center staff. Duration of the temporary positions range from three to six months and the trainees receive wages.

Employment



Supported Employment refers to competitive employment occurring in integrated work settings and being performed by individuals with handicaps for whom either competitive employment has traditionally occurred or competitive employment has been interrupted or become intermittent as the result of a severe disability and which, because of their handicaps, need ongoing job coaching, psycho-social and other support services to perform such work.

Sheltered Workshop Employment refers to an occupation-oriented facility operated by a not-for-profit corporation, which, except for its staff, employs only persons with a handicap and has a minimum enrollment of at least fifteen employable handicapped persons (Section 178.900 RSMo.). To be eligible persons must be certified by the Division of Vocational Rehabilitation .

Day Programs maintain the intellectual, emotional, social, vocational, and physical capacity of a person who may have received services from an acute rehabilitation, functional living rehabilitation and/or transitional living program, and is unable to maintain a job or participate in a vocational or educational program.

The Current Service System: Employment

Supported Work

The Missouri Division of Vocational Rehabilitation receives federal funding for time limited supported work programs. One of the requirements is a demonstration that long term support is available to assist the person in maintaining employment before federal dollars can be used. Supported work programs have developed in Missouri for persons with developmental disabilities or mental illness as the Missouri Department of Mental Health and local mill tax boards are able to provide for long term support. However, supported work funding has not been readily available for persons with head injury due to the lack of assurance for long-term support.

During the 1989 legislative session, additional funding was appropriated to the Missouri Office of Administration, Division of General Services for long-term support services to enable persons with head injury to participate in the supported work program funded initially by the Missouri Division of General Services.

The Office of Administration, Division of Purchasing issued a Request For Proposal (RFP) in May 1989, soliciting long-term support programs. During FY'90, eight programs were awarded long-term supported work contracts: Rehabilitation Institute, Kansas City; Blue Valley Head Injury Center, Kansas City; Advent Enterprises, Columbia; Goodwill Industries, St. Louis; Life Skills Foundation, St. Louis; MERS, St. Louis; Franklin County Board for the Handicapped, Union; and Missouri Easter Seals Society, Southeast, Cape Girardeau.

Long-term services being provided include individualized job coaching, group job supervision (enclave model), some case management, and in-home support.

Residential Services/Supported Living

Ideally, a person suffering from a head injury would return to his/her natural environment following medical and rehabilitation care whether that be to live with a spouse, other family member(s) or independently/semi-independently. For those who are unable to return to his/her natural environment independently, then some type of housing or support which provides supervision and protection may be needed. Others may require continued rehabilitation, medical, or specialized care provided in a residential setting.

Home health care agencies provide three types of

services: (1) In-home visits by nurses, which generally are covered by Medicaid or Medicare; (2) homemaker program providing non-medical assistance, such as grocery shopping, to elderly or handicapped persons who would otherwise be in nursing homes, which is a Medicaid service; and private duty (8 hours at a time), which is generally covered by private pay, insurance and sometimes Medicaid.

Personal Care Assistance provides in home assistance which may include help with dressing, bathing, eating or other personal care activities, thus enabling a person to reside in a semi-independent living situation.

Independent Living Centers may provide counseling and /or supervision on a periodic basis, thus assisting the person with head injury to live semi-independently.

Supported Housing is a consumer oriented approach to housing which provides the supports necessary to live successfully in a chosen environment. It emphasizes the use of existing housing in the community, and it separates the treatment aspects from the housing aspect.

Supervised Living Arrangement is a place of residence that substitutes for the individual's own home or for the home of the individual's family. It should provide environments that are conducive to the development of adaptive behavior, self help and independent living skills. The residence also should facilitate, to the greatest possible extent, continuity with culturally normative living patterns. It should be located within the community and should include both generic and specialized services.

Structured Residential Placement provides 24-hour care and treatment for those individuals who manifest severe behavior problems. The setting may exist independently or as a part of a larger program.

Coma Management/Nursing Programs may accept such individuals once they are medically stable and attempt to achieve improvement by the use of various stimulus techniques. Skilled nursing care and physical therapy are important elements of these programs.

Respite Care provides temporary relief to the family, thus enabling the family to care for the person in his or her home.

Current Service System--Residential Services

Personal Care Assistance/Independent Living Centers

There are five independent living centers throughout the state which provide in varying degrees personal care, in-home care and other independent living services to persons with disabilities. Some of the centers do offer their services to persons with head injury. State funding is appropriated to the Missouri Division of Vocational Rehabilitation for personal care attendant services. The independent living centers administer these funds at the local level. Services have been limited due to the appropriation.

Services for Independent Living, an independent living program in Columbia formerly known as Opportunities Unlimited, is under contract with the Missouri Office of Administration, Division of General Services, to provide in-home, counseling and other supervision for those living independently/ semi-independently. Some of the home health care agencies also provide in-home care (medical) and homemaker services for persons needing such care in the community.

Supervised/ Supported Living Programs

Supervised or supported living programs designed to meet long term housing needs have yet to be developed statewide for survivors of head injury in Missouri. Persons requiring long term care or specialized care have generally sought services from the Missouri Department of Mental Health through its Division of Comprehensive Psychiatric

Services and Division of Mental Retardation and Developmental Disabilities and from nursing homes. Some have sought services outside of Missouri.

A supported housing program in St. Louis offered by Larson and Associates, Inc, began in December 1989, at the request of the Department of Mental Health in order to provide more appropriate services for a department client with a head injury. Larson and Associates is assisting ten to twelve persons with head injury by coordinating community support services. The funding base for the program is from the Department of Mental Health, Division of Comprehensive Psychiatric Services and private pay.

Structured Residential Placement

St. Louis State Hospital, a facility operated by the Department of Mental Health, has developed a head injury unit to serve some head injury patients with aggressive or severe behavior problems. The unit is for men only as the facility does not have the staff to develop a separate program for both men and women. The unit was originally established to serve the hospital's patients with head injury who had been at the hospital for some time and did not benefit from treatment for mentally ill patients. Some of the patients have been since been discharged and the unit now accepts referrals. The Department of Mental Health and the Department of Health coordinates services provided by the Missouri Rehabilitation Center and St. Louis State Hospital and

.

During the 1989 legislative session, the Missouri Rehabilitation Center, operated by the Missouri Department of Health, received funding for four beds for persons with head injury with severe behavior problems.

Persons with head injury who also exhibit aggressive and inappropriate behavior find it difficult to locate programs or community support services due to lack of staff or adequate facility or failure to meet eligibility criteria. The commitment law which allows the court to commit mentally ill persons who are considered dangerous to self or others does not apply to persons with head injury. Persons who require such a program tend to be shifted from facility to facility. Others who are not able to access any program tend to be difficult for the family and the community to manage.

Coma Management Programs

Although the Missouri Rehabilitation Center has a few clients who are comatose or in a semi-coma, the facility has not held itself out as having a coma management program. A few nursing homes have accepted patients coming out of coma, but generally the nursing home industry does not believe nursing homes have the staff, in part, due to the costs and reimbursement, to handle this level of care. St. John's Hospital in St. Louis has recently developed a coma management unit and SSM Rehabilitation Institute and Rebound, Inc. accept coma patients.

Community Support Services

Community support services provide ongoing or intermittent support to survivors of head injury and their families following rehabilitation, thus, enabling them to live in the community on their own or with family or other assistance. These services may exist independently or be part of a larger program. Such services provide ongoing or intermittent support in several areas including recreation, counseling, transportation, therapies, and other support services. Case management has been categorized as a support service. As in other fields, case management is viewed by the Missouri Head Injury Advisory Council as playing a major role in the provision of services and should be addressed as a major component of the service delivery system.

Counseling is an individual or a family intervention to provide psychological support, direction, or change with regard to feelings or thoughts elicited or resulting from brain injury.

Family Training is a program of training for family members which provides skills to assist the person with a head injury in the family and outside of the home, emphasizing a program of structural activities. In essence, family members are trained to become their own service provider.

Follow-Up provides for the monitoring of clients who have returned to school, home or employment to program. It may be a component of a Functional Living Rehabilitation, Transitional Living or Pre-

Vocational Training/Pre-Employment training program.

Transportation refers to the provision of necessary travel accommodations for persons with brain injury to and from places where they are employed or where they receive other services. Transportation may include the provision of driver's education, adaptive automobile devices, and/or training in the use of public transportation systems.

Recreation/Socialization activities may be provided in specialized programs specifically for persons with head injury or in existing community programs.

The Current Service System: : Support Services

Recreation

The Missouri Head Injury Association sponsors a camp, Wilderness Retreat, during the summer with some assistance from the state through a contract with the Missouri Office of Administration, Division of General Services. The camp, which consists of two one-week sessions, not only provides socialization and recreation for those who have sustained a head injury, but also provides respite for their families and caretakers.

Counseling/Family Support/Referral

Some families and persons with head injury seek counseling services through community mental health centers throughout the state and from private counseling services. The Missouri Head Injury Association through its local chapters offer family support and referral services. The council also provides referral services.

Case Management & Rehabilitation Program Planning

Case management is an encompassing process which is the link between the client and the service delivery system. It is a method that analyzes client needs and assesses area resources in order to provide, procure, purchase, and coordinate services for persons with a brain injury. The process must be flexible to allow for the reformulation of service plans relative to changing client needs. It allows clients to remain in their least restrictive environment and fosters the concept of normalization. Case management generally consists of the following functions: (1) Intake; (2) service planning (developing an individualized rehabilitation plan); (3) service coordination; (4) service monitoring/ quality assurance; (5) supportive counseling; and, (6) client advocacy.

Evaluation/Assessment services consist of the initial clinical interview for (1) determining the level of cognitive, speech/communication, independent living skills, emotional, physical and/or vocational functioning; (2) determining the need for rehabilitation or specialized service(s); (3) and/or development of a rehabilitation plan. An interdisciplinary team should provide the initial or ongoing assessment and develop treatment/rehabilitation plans based upon the assessment. Initial or ongoing assessment should address the following:

- Medical and neurological issues
- Health and nutrition
- Sensorimotor capacity including gross and fine motor strength and control,sensation, balance, joint range of motion, mobility and function
- Cognitive capacity
- Perceptual capacity
- Communicative capacity
- Affect and mood
- Interpersonal and social skills
- Behavior
- Activities of daily living including self-care, home and community skills
- Recreation and leisure time skills
- Educational and/or vocational capacities
- Sexuality
- Family
- Legal competency of the person
- Community reintegration, including appropriate post-discharge services
- Environmental modification
- Adjustment to disability

Program Evaluation/Standards/Certification are the measures against which a program organization or agency is compared to monitor and assess its common practices, quality, and effectiveness in carrying out program and client goals and objec-

tives. The Commission on Accreditation of Rehabilitation Facilities (CARF) has developed national standards for some types of brain injury programs. The standards are voluntary and an agency can apply to CARF for accreditation.

The Current Service System: Case Management & Program Planning

Ideally, case managers for persons with head injury would be available throughout the state to assist families and survivors in accessing services and funding necessary for the client to receive rehabilitation and/or to remain in the community. Although case management services are provided by some individual providers, case management is not provided, generally, independent of providers for persons with head injury.

For persons who meet the eligibility criteria for the Department of Mental Health, Division of Mental Retardation and Developmental Disabilities, case management services are provided through the division's eleven regional centers for the developmentally disabled. However, services which may be prescribed by the regional centers' treatment team may not be available for persons with head injury so that the clients with head injury may be either referred to programs for persons with developmental disabilities or are not provided services.

Programs under contract with the Missouri Office of Administration, Division of General Services are required to develop and implement individual treatment/rehabilitation plans according to guidelines provided in the contract. Facility standards with regard to fire and safety are also included in the contracts for programs to meet. The Commission on Accreditation of Rehabilitation Facilities has developed standards for brain injury rehabilitation (acute and outpatient) programs and facilities may subscribed to the standards. The Missouri Department of Social Services, Division of Aging, licenses nursing homes and the Missouri Department of Health licenses hospitals and rehabilitation hospitals. There are no state standards or licensing requirements for residential programs, day programs or other specialized services serving clients or patients with head injury.

Pediatrics

Although traumatic head injury is a major cause of disability for children, many professionals interacting with children with head injury are often times unaware of the consequences of head injury. Their needs often go unmet. There needs to be strong coordination and interaction between rehabilitation professionals and the public schools for those children who are school age in order to transition them back to school.

While school teachers and therapists need to be informed in order to appropriately address educational needs, many times the families need other services which are not traditionally provided in the school setting, such as case management, respite, counseling, and assistance in managing behavior at home.

For some who are seriously injured families need medical assistance either in the home setting or in a setting designed to provide a high level of medical care.

The Current Service System: Pediatrics

Ranken Jordan in St. Louis provides residential care for children with medical needs, including children with head injury. In 1988, legislation passed in Missouri which recognized nursing homes for children.

The Medicaid program, Early and Periodic Screening, Diagnosis and Treatment, provides an array of services which are documented through the screening process for children up to age 21.

Education

The Missouri Department of Elementary and Secondary Education, Division of Special Education, has assigned staff to assist school districts with the provision of educational services to students with head injury. The division has prepared a manual, *Developing Individual Education Plans for Students Who Have Suffered Traumatic Head Injury*, outlining educational responsibilities to be used in conjunction with the manual developed by the National Head Injury Foundation.

Chapter Two:

Fiscal Year 1990 Action Plan Update

Issue 1: Planning for a Statewide Service Delivery System

Background

Programs for survivors of head injury and their families are relatively new with the majority of programs, mostly private, having been developed the past ten years. In 1984, the Missouri General Assembly passed a Senate Resolution calling for the establishment of a Joint Interim Committee to study the needs of persons with head injury and their families. The Joint Interim Committee not only learned about the extent of Missourians with head injury, causes of head injury and the resulting problems, but also how lacking and fragmented state and private services were. The state of Missouri began addressing the lack of services in 1985 by creating the Missouri Head Injury Advisory Council on March 5, 1985, upon the recommendation of the Joint Interim Committee. Also at the recommendation of the Joint Interim Committee, the state appropriated some state funding specifically for head injury services for Fiscal Year 1986.

An appropriation was made in the supplemental appropriation bill in Fiscal Year 1985 to the Office of the Administration for staff and necessary expenses for the council, which was charged with the responsibility of studying and making recommendations for improving services for persons with head injury. The council was administratively assigned to the Office of Administration as the problems and service needs associated with head injury crosses several agencies, yet no state agency has primary responsibility for providing services.

The Office of Administration provides a forum for the different state agencies along wiith consumers, parents and other professionals to coordinate and to plan for state services. No state has developed a comprehensive statewide service system, although many states have established councils or task forces to address planning and have begun funding services on a limited basis.

In general, it has been difficult for persons with head injury to access the various state/federally funded programs due to eligibility criteria. Many of the programs offer services based on financial eligibility and others offer services to special populations groups which do not include head injury. The council's role has been to facilitate policy making at the state level so that services can be coordinated at the local level.

Many fields use a case management system to coordinate and monitor all services to meet the full range of needs of an individual client. Case management can include the following general functions: (1) outreach, (2) intake, (3) assessment, (4) service plan development, (5) service coordination, (6) advocacy, (7) crisis intervention and (8) monitoring. The purpose of case management is to ensure that clients receive appropriate services. Although some head injury programs, medical programs, insurance, mental health, vocational rehabilitation and others use a case management service within their own programs, there is not a statewide case management system independent of providers for survivors of head injury. Such a system would allow for coordination of services which may be provided by different agencies.

Since the state has become more involved with the provision of services and with the head injury population, good planning is essential in order to maximize resources and to reduce potential duplication. Planning includes:

✔Identifying the service population

✔Identifying/defining service needs

✔Identifying gaps in the service system

✔Prioritizing services

✔Identifying barriers to services

✔Determining how to develop and to distribute them to ensure overall accessibility and availability.

Accomplishments

The council has conducted and continues to be involved with projects to identify the extent of head injury, services needed, services available and to coordinate and maximize existing services available for other disability populations. The council provided assistance to the Department of Health and the Office of Administration, Division of Purchasing, in developing Request for Proposals for the head injury service appropriation awarded to the department for FY'86. (For FY'86, $500,000 was appropriated.) The council viewed the process as an opportunity for providers to develop innovative approaches for services. During this process, it was noted by the council that there was a lack of common terminology for programs and services and differing perceptions as to how services should be provided.

Defining/Identifying (Incidence and Prevelence) Persons with Head Injury

To assist with program planning and development the Missouri Head Injury Advisory Council first defined head injury and services which may be needed. At that time (fall 1986), the National Head Injury Foundation had not developed a definition for head injury. After reviewing definitions used by some states, the council defined the term "head injury". This definition was included in the legislation establishing the head and spinal cord injury registry. The Department of Health, Division of Health Resources has released the data collected from the registry for the past two calendar years (1988 and 1989). (The definition for head injury is also used in the request for proposals for head injury services issued by the Missouri Division of Purchasing for the Office of Administration, Division of General Services.)

The Division of General Services, upon the recommendation of the council, entered into a contract with the University of Missouri-Columbia, School of Journalism, Bureau of Media Research, to conduct a statewide poll to determine public awareness of head injury and the prevalence of head injury. The council developed the questionnaire and the University conducted completed the report in the fall of 1988.

Also during FY'86, the council conducted a survey to determine how many persons with head injury have sought services from the Department of Mental Health facilities and community programs as well as from nursing homes and home health care agencies. The report, *Survey of Missourians with Severe Head Injury Served by Mental Health, Home Health & Nursing Home Facilities,* indicated that persons are being served to some degree. The report indicated that most of the persons receive maintenance services, but few receive specific treatments directed at brain injury induced deficits. Over half of the persons surveyed will still need services in five years. The lack of a state statutory definition at that time presented some limitations. To be eligible for services by the Missouri Department of Mental Health, Division of

Comprehensive Psychiatric Services or the Division of Mental Retardation and Developmental Disabilities, persons must fit the definition of mentally ill, mental retardation, or developmentally disabled and require the services offered by the department. Persons admitted or placed by the department are usually diagnosed accordingly .

The Department of Health, Division of Health Resources, annually surveys nursing homes and after the survey was undertaken, included a question regarding the numbers of persons with head injury served in the nursing home. The Division issues a report annually and can produce a report with a list of nursing homes reporting patients with head injury.

The Division of Vocational Rehabilitation also codes head injury for clients receiving vocational rehabilitation services.

Defining/Identifying Service Needs

During FY'86, the council identified and defined services and programs which may be needed starting with acute brain injury rehabilitation, functional living rehabilitation, transitional living, residential, case management and community support services. The report, *Proposed Service Delivery System for Rehabilitation of Missourians with Head Injury,* was distributed statewide for comment. For FY'88 head injury contracts, these definitions were incorporated in the Request for Proposals. On January 19, 1988, the council co-sponsored with the Office of Administration, Division of General Services, a public hearing to obtain recommendations for service priorities for the appropriation to the division for head injury services.

Service Recommendations

During FY'87, the council through its committees, developed its *Action Plan* containing goals and objectives for developing and improving services. This plan was included in the FY'87 *Annual Report* and became the guide for its activities. The goals and objectives are now a part of each annual report.

The council chairman appointed a Task Force on Service Delivery Systems Recommendations May 1988 to study and to recommend which agency should have primary responsibility for serving persons with head injury. The Task Force recommended that the Department of Health should have primary responsibility for developing and providing services to survivors of head injury. Legislation was introduced in the 1989 and 1990 sessions to establish a division of head injury rehabilitation and the bill failed to pass during either session.

Plan Initiatives

Three-Year Goal: To assess service needs of survivors of head injury.

First-Year Objectives	**Fiscal Year 1990**
1. Rank service needs based on council knowledge and/or in consultation with other organizations.	**Assess Service Needs**
2. To develop or to assist others to develop a tool or method to assess service needs comprehensively.	
3. To develop an inventory of services currently provided.	

Progress in Meeting FY'90 Objectives: In order to develop a service inventory/ directory a survey was sent to known head injury providers, nursing homes and hospitals during FY'89. The directory has not yet been published. A client/patient profile form was developed by council staff for head injury programs under contract with the Office of Administration, Division of General Services to complete in order to make some determination as to the average age, sex, length of time between acute care and the programs services, services needed following discharge, etc. The form was distributed for FY'90. The council housing task force is developing a questionnaire.

Second-Year Objectives **Fiscal Year 1990**

1. To continue comprehensive assessment of needs.
2. Work with the Department of Health to develop research projects for purposes of assessing needs utilizing registry data.
3. Work with the Missouri Rehabilitation Center to determine the type of services patients discharged from the Center will need in order to return to the community.

Progress in Meeting FY'90 Objectives: The Department of Health with support from the council has received a contract from the National Highway Traffic Safety Administration to follow a selected group of patients with head injury after hospital discharge to assess service needs.

Third-Year Objectives **Fiscal Year 1991**

1. To continue or to support research projects.
2. To rank service needs by service catchment area based on survey results, current services provided and data from head injury registry.

Three-Year Goal: To determine roles of existing state agencies in providing directly or indirectly services to survivors of head injury and their families.

Roles of State Agencies

Second-Year Objectives **Fiscal Year 1990**

1. To develop agreements as to how services are to be provided and alternatives for departments when the department's services are not appropriate.
2. To develop a referral system for state agencies and non-state agencies.

Third-Year Objectives **Fiscal Year 1991**

1. To determine which, if just one, state agency should have primary program responsibility for survivors of head injury.

Progress in Meeting FY'90-91 Objectives: The council has encouraged the Department of Health, Missouri Rehabilitation Center, and the Department of Mental Health, St. Louis State Hospital, to develop an interagency agreement so as to coordinate services. The departments are in the process of developing an agreement. The Department of Mental Health, Division of Comprehensive Psychiatric Services solicited input from the council as to the role of the division in providing services for inclusion in the state mental health plan. The council chairman appointed a Task Force on Service Delivery Systems Recommendations to study and to recommend which agency should have primary responsibility for serving persons with head injury.

Case Management

Four-Year Goal: To develop a case management model system.

First- through Fourth-Year Objectives **Fiscal Years 1990-1993**

1. To work with the Department of Mental Health to establish a pilot project under the Medicaid waiver.
2. To develop budget requests for case managers based on the council's study.
3. To support legislation establishing case management services.

Progress In Meeting FY'90-93 Objectives: The Task Force on Service Delivery Systems recommended that a division of head injury and rehabilitation be created in the Department of Health with case management as a central part of the service system. The Office of Administration did not recommend a FY'90 budget request for a case manager for the head injury program.

Issue 2: Prevention

Background

The incidence and severity of head injury can be reduced through prevention and early intervention activities. Half of all head injuries are caused by automobile crashes. The other half are are due to recreational injuries, assaults, weapons, falls, and industrial injuries. Injuries have traditionally been viewed as unavoidable accidents rather than a health problem. Yet, injuries are the leading cause of death and disability in children and young adults and cause the loss of more working years than all forms of cancer and heart disease combined.

In 1983, Congress enacted a law authorizing the secretary of the Department of Transportation to request a study on trauma (injury) by the National Academy of Sciences. The committee issued a report in 1985, *Injury in America: A Continuing Health Problem.* One of the findings of the committee was the lack of data necessary to allow for the study of the epidemiology of most injuries. There is no national mechanism for collecting data regarding the number of head injuries, causes, number of persons disabled due to head injury and so forth. The committee believed that systematic data collection is essential for planning and evaluating prevention programs.

The National Committee for Injury Prevention and Control through its publication, *Injury Prevention: Meeting the Challenges,* has noted the need for a lead agency or organization which can serve as a community or statewide focal point for injury prevention expertise. In Missouri, as in many other states, the Division of Highway Safety leads the effort to reduce traffic-related injuries and deaths. The Department of Health also assumes a role in injury prevention.

Prevention efforts may include public education, public policy through laws designed to reduce injuries, and providing automatic protection by product and environment design.

Accomplishments

The Missouri Head Injury Advisory Council co-sponsored with the University of Missouri a conference on prevention October 1985. The conference allowed for the discussion of Missouri's ability to gather data, its emergency medical services program, trauma center status, and programs focusing on prevention activities.

Data

During the 1986 legislative session, the council initiated legislation, which passed, mandating hospitals to report head and spinal cord injuries to the Department of Health, which in turn, is to report head injury data to the Missouri Head Injury Advisory Council. During FY'87, the council worked with the Department of Health and others to develop the reporting form. The registry was implemented by the department July 1, 1987. The department has provided in-service to the hospitals with regard to completion of the form and has continued to work with the hospitals to obtain consistency in reporting. The department will collect the data on a calendar year basis and will report accordingly. Data is now available from calendar year 1988 and 1989.

With assistance from the Missouri Division of Highway Safety and support from the Missouri Head Injury Advisory Council the Missouri Department of Health received two contracts from the National Highway Traffic Safety Administration for purposes of researching costs injuries as the result of motor vehicle accidents. Missouri is one of four states to receive a contract to link data systems from the scene of the accident to the hospital emergency department. It is the only state to receive an additional contract to collect cost data not only from the accident scene, but also from the emergency room through hospital discharge. The department will survey a selected group of patients after hospital discharge to see what additional services, if any, the person has received. The department will conduct the three year study in cooperation with the Division of Highway Safety, Missouri State Highway Patrol Statistical Analysis Center, Missouri Hospital Association and the Missouri Head Injury Advisory Council.

The University of Missouri-Kansas City in cooperation with Argus Computing, Inc. developed a pilot trauma/ injury database January 1986. Three hospitals participate in the Kansas City project and record all trauma, not just head trauma. The UM-KC project was developed independently of the Missouri Head Injury Advisory Council. The project staff, however, are very cooperative and supply data to the council on request. The staff also participated in the development of the state reporting form for the head and spinal cord injury registry and assisted the Department of Health with the in-service training for hospital personnel with regard to the completion of the form.

State Laws

Missouri has several laws designed to reduce fatalities and injuries. These laws include: Mandatory child restraints, mandatory seat belts for passengers in the front seat of automobiles, mandatory helmets for motorcycle riders, and stiff penalties for DWI (Driving While Intoxicated). Legislation passed during the 1988

session addressing safety for riders of ATVs (all terrain vehicles). Legislation also passed during the 1988 session repealing the sunset provision of the seat belt law.

Prevention Programs/Efforts

There are several education programs promoting safety habits conducted by local and state agencies including: Missouri Division of Highway Safety, Missouri State Highway Patrol, Missouri Safety Belt Coalition, Missouri Safety Council, SAFE Kids, and the Missouri Head and Spinal Cord Injury Prevention Project, conducted by the University of Missouri-Columbia , and regional head and spinal cord injury prevention projects replicating the program developed by the University of Missouri-Columbia.

The council has supported the Missouri Head and Spinal Cord Injury Prevention Project in its efforts to inform public school students as to the need for exercising caution and good judgment in order to prevent unnecessary injuries. The council has advocated for federal funding and for state funding to evaluate the effectiveness of the program and to expand the program. During the 1988 session, the council co-sponsored with other safety groups a breakfast for legislators featuring the prevention project. Members of the council testified before the Missouri Board of Health and the House Appropriations Committee on Mental Health for state funding for the program. The Department of Health received state funding for the first time in Fiscal Year 1988 for purposes of expanding the program. The program, which has expand largely through local efforts, has been replicated in Kansas City, St. Louis, Cape Girardeau, Springfield and Joplin.

Prevention Coordination

Also, the council networks with other safety groups with prevention efforts including the Missouri Division of Highway Safety Missouri Safety Council and the Missouri Safety Belt Coalition, of which the council is a member. In June 1986 the council director and two council members addressed the state and local safety councils as to how to use head injury data in their safety campaigns. The council also worked with the various safety groups to compile information supporting helmet and seat belt use. The council has joined the national campaign, 70 by 90, which is striving to meet 70 percent correct child safety seat and adult safety belt use by 1990.

In 1989, the Department of Health, Division of Health Resources received a four year capacity building grant from the Centers for Disease Control. The Division established a section on injury control and a state advisory committee on injury control was set up and appointed by the director of the Department of Health. Two members of the Missouri Head Injury Advisory Council and the staff for the head injury advisory council were appointed to the committee.

Public Education

Since January 1986, the council has published a newsletter called the *Quarterly.* It has sponsored five major conferences held annually in the spring beginning 1986. A panel on prevention is featured during each of the conferences. The council has developed a brochure and display board to use at conferences. The council maintains resource files and distributes information on request. Council staff arranged the Governor's proclamation proclaiming October as Head Injury Awareness Month. For 1989 Head Injury Awareness Month the council developed an Idea Sampler for use by local organizations and chapters of the Missouri Head Injury Association.

In 1989, the council staff arranged the Governor's proclamation and the Missouri House of Representatives and Senate courtesy resolutions honoring the Run to Daylight campaign, a head injury awareness project conducted on behalf of the National Head Injury Foundation in May 1989. Also during that year, the council also arranged for a state senatorial resolution recognizing February 7-13 as National Child Passenger Safety Awareness Week.

Plan Initiatives

State Laws

Five-Year Goal:To support legislation which reduces fatalities and injuries.

First-Year Through Fifth-Year Objectives **Fiscal Year 1990-1994**

1. To continue to oppose the helmet repeal.
2. To continue to oppose the seat belt repeal in cars and to support seat belts in trucks.
3 To continue to support legislation prohibiting children from riding in the back of pickup trucks.
4. To continue to study the issue of seat belts for school buses.
5. To support legislation which strengthens the DWI law by eliminating hardship drivers license's and lowering the blood alcohol content from .13 to .10 for administrative revocation.
6. Support legislation requiring children to wear bicycle helmets.

Progress in Meeting FY'90 Objectives: The council supported legislation requiring seat belts in pickup trucks, and opposed the helmet repeal legislation The council and other safety organizations the year before developed a brochure regarding motorcycle helmets.

Public Education

Five-Year Goal:To inform the public of the causes and treatment/rehabilitation of head injuries.

First- through Fifth-Year Objectives **Fiscal Year 1990-1994**

1. To continue publishing the newsletter, press releases and other informational materials.
2. To maintain a resource file on current literature and audio-visual materials.
4. To develop a speaker's bureau in coordination with the Missouri Head Injury Association.
5. To develop brochures regarding the incidence and causes of head injuries in Missouri.
6. To encourage other organizations promoting safety to incorporate facts on

head injury along with fatalities in their educational efforts.

7. To develop materials for interested groups/organizations to promote October Head Injury Awareness Month.

8. To continue to support funding to allow the Missouri Head and Spinal Cord Injury Prevention Project operated by the University of Missouri-Columbia to expand statewide.

9. To encourage school districts to invite the Missouri Head and Spinal Cord Injury Prevention Project to conduct its program during school assemblies.

10. To include prevention on the agenda of the annual council conference.

Progress in Meeting FY'90 Objectives: The council continued publishing the newsletter, issued press releases, and appeared on radio and television news segments. The council office maintains a resource file and distributes information regularly. The council participated in the proclamation signing proclaiming October as Head Injury Awareness Month. The council developed an *Idea Sampler* for use by local safety organizations and head injury rehabilitation and advocacy agencies.

Two-Year Goal: To determine incidence and prevalence of head injury.

Incidence/ Prevalence of Head Injury

Second-Year Objectives **Fiscal Year 1990**

1. Using data from the trauma registry, determine the primary causes of injuries in Missouri, the number of injuries, the severity of injuries, and possibly the prevalence of head injury.

Progress in Meeting FY'90 Objective: The Department of Health released information from the Missouri Head and Spinal Cord Injury Registry representing data collected in calendar year 1988. The information was presented during the Fourth (partial results) and during the FifthAnnual Missouri Head Injury Advisory Council Conferences and has been routinely presented to the council at its meetings. The data was used to support the need for the capacity building grant received by the Department of Health from the Centers for Disease Control. The data is being used to develop the state injury prevention plan. Through that planning process, the data is being further analyzed to address primary causes of injuries and severity of injuries.

Three-Year Goal: To determine effectiveness of prevention programs.

Effectiveness of Prevention Programs

Third-Year Objectives **Fiscal Year 1991**

1. Using registry data and other informational systems, study the effectiveness of prevention programs and legislation designed to prevent injuries and fatalities.

2. Work with the University of Missouri-Columbia to study effectiveness of the Missouri Head and Spinal Cord Injury Prevention Project.

3. Work with the new Missouri Injury Control Program to evaluate effectiveness of head injury prevention programs.

Progress in Meeting FY'90 Objectives: The council has written several letters supporting grant applications submitted by the Department of Health and the University of Missouri-Columbia for purposes of evaluating the effectiveness of prevention programs, specifically the program conducted by the University. The Department of Health received a four year injury control grant from Centers for Disease Control for purposes of establishing a state injury control program comprised of staff and an injury control council to plan, evaluate and coordinate injury prevention projects. CDC awarded the grant beginning fall 1989.

Issue 3: Early Rehabilitation Care (EMS) and Rehabilitation Services

Background

The outcome of injury depends not only on its severity, but also on the speed and appropriateness of treatment. Rehabilitation should first begin with the emergency medical services (EMS) team at the scene of injury. Proper attention should be provided in order to prevent further injury. Trained paramedics are able to attend to airways, treat shock, and monitor a patient's condition. They can also notify the receiving hospital regarding the patient's condition and the estimated time of arrival.

In order to minimize injury, it is important to have a system in place which can allow for injury management at the scene of the injury and facilitate rapid delivery of the patient to a hospital which can provide the needed care.

Often referred to as the "golden hour," medical care provided to the patient during the sixty minutes following the accident is critical and often determines whether the patient survives the injuries. Designated trauma centers are vital to the system. Once a severely injured person arrives at a hospital, he or she will generally need the services of various specialists experienced in injury management.

Part of the challenge of providing adequate care for persons who sustain traumatic head injury is the diversity of needs after injury. Post-injury can range from full time care to community re-integration. The order in which services are used can also vary; some people will move from acute medical care into community integration while others may require extended periods of nursing care before they benefit from rehabilitation. Many persons require more than one type of treatment simultaneously. Thus, services must be flexible, but also allow for the most frequent progressions.

Rehabilitation programs for persons with head injury are relatively new. Private programs have developed across the country over the past ten years, usually focusing on coma management, functional living rehabilitation, and/or transitional living programs. A few companies have began developing supervised living programs. These programs generally rely on patients/clients who have the ability to pay. In some states, head injury programs have been able to be reimbursed under the state's Medicaid program for

certain services. For those persons who do not have the ability to pay, whose insurance will not cover the services, whose insurance has been exhausted, or do not have any other source such as Workers' Compensation, rehabilitation services are extremely limited.

Many persons who suffer from a head injury may return to employment. Others, with vocational or pre-vocational rehabilitation—which may be in addition to rehabilitation as described above, may return to employment. Still, others will need either supported employment or sheltered employment or day programs after rehabilitation. Day activity programs in this sense would maintain the intellectual, emotional, social, vocational and physical capacity of persons who are not readily able to maintain any type of employment. The program has a different purpose than a day treatment (functional living rehabilitation or transitional living) program.

Accomplishments

In 1987, legislation passed establishing a state trauma center system. The Department of Health, Division of Health Resources is responsible for trauma centers being reviewed and designated across the state. The Missouri Head and Spinal Cord Injury Registry data not only collects data with regard to the number of injuries, but also with regard to method of transportation, length of time in the emergency department, medical treatment provided, disposition of the patient, and arrival time of the surgeon. The data allows the department to evaluate the effectiveness of the EMS system in saving lives and preventing further injury.

In Missouri, the state provides some rehabilitation services through the Missouri Rehabilitation Center operated by the Missouri Rehabilitation Center, and through state contracts with the Office of Administration. The Missouri Medicaid Program includes post acute rehabilitation in a day program setting (functional rehabilitation) as an eligible service as the result of legislation which passed in 1988.

In addition, The Missouri Department of Elementary and Secondary Education, Division of Vocational Rehabilitation, provides vocational rehabilitation services for those persons who may be determined to be employable. For those persons who are not quite ready for vocational rehabilitation and do not need the intense level of rehabilitation provided in functional living rehabilitation, pre-vocational training or work readiness may be needed. The Division of Vocational Rehabilitation has assigned a vocational rehabilitation counselor in each district office to work with clients with head injuries. The division provides ongoing in-service training regarding head injury to counselors. Part of the in-service training has included sending counselors and central office staff to the annual conferences sponsored by the council. Some of the division staff have assisted with presentations and with making suggestions for workshop topics.

As the result of federal legislation, the Missouri Division of Vocational Rehabilitation administers the supported work program. Most persons with head injury have been unable in the past to access the supported work program due to lack of long term support services which are necessary in order to participate in the federal program. However, as the result of an appropriation for long-term support for persons with head injury for FY'90, eight supported programs have been developed.

The Missouri Head Injury Advisory Council initiated legislation introduced during the 1987 legislative session to allow sheltered workshops to receive a portion of the state subsidy for those clients who work less than six hours a day. This was introduced and passed to give the workshop staff flexibility to tailor the workshop program for those who may not be able to work a six hour day or who may require programming in conjunction with part time sheltered employment.

Plan Initiatives

Enhance EMS Care

Three -Year Goal: Enhance emergency medical services and early trauma care in order to reduce secondary injury.

Third-Year Objectives **Fiscal Year 1991**

1. Using data from the registry, work with the Department of Health and the State Emergency Medical Services Council to study the effectiveness of Missouri's emergency medical system and the trauma center system.

Rehabilitation Programs

Four-Year Goal: To develop an array of rehabilitation programs accessible statewide.

First-Year Objectives **Fiscal Year 1990**

1. To include in the service inventory the number, location, eligibility requirements and type of rehabilitation programs currently available statewide.
2. To address rehabilitation programs in the needs assessment survey.
3. Determine the need for rehabilitation programs based on needs assessment survey, service inventory and trauma registry.

Progress in Meeting FY'90 Objectives: During FY'89, surveys were sent to providers and other organizations to determine the extent services are being provided and if services are being planned for the future. The survey included requests for information with regard to service catchment area, eligibility criteria, and methods for payment. That information has yet to be compiled.

First- through Fourth-Year Objectives **Fiscal Years 1990-1993**

1. Continue to determine the need for rehabilitation programs based on needs assessment survey, service inventory and trauma registry.
2. Prepare and submit budget request to establish a transitional living (residential) program.
3. Support expansion of the head injury programs, including the transitional living programs, at the Missouri Rehabilitation Center, Mt. Vernon.
4. Prepare and submit budget requests for other rehabilitation programs based on needs assessment.

Progress In Meeting FY'90-93 Objectives: Council members testified before the Missouri Board of Health and the Missouri Department of Health regarding the need for expanding the Missouri Rehabilitation Center. The council also testified before the Missouri House of Representatives Appropriation Committee on Mental Health and Health with regard to the Missouri Rehabilitation Center. The Office of Administration, Division of General Services submitted budget requests to expand services to include transitional living and supported work programs (long-term support) The budget item for long-term support in conjunction with supported employment was approved.

Two-Year Goal: To promote coordination between acute hospitals and acute brain injury rehabilitation programs and between acute brain injury rehabilitation programs, functional living, transitional living programs and community support programs.

Program Coordination

First- through Second-Year Objectives **Fiscal Years 1990-1991**

1. Distribute information regarding availability of services compiled as the result of the service inventory to social services department of hospitals.

2. Require programs receiving state funding from the Missouri Office of Administration, Division of General Services to have written agreements and/or policy regarding the relationships between the facility and rehabilitation programs, community support programs, acute hospitals and/or educational programs. The programs should be able to document the results of the agreements.

3. Conduct workshops regarding availability of services.

4. Promote awareness of programs through newsletter.

Progress In Meeting FY'90-91 Objectives: The Request for Proposals for head injury services require contractors to have written agreements between the facility and various programs. The council has encouraged the Department of Mental Health and the Department of Health to develop an interagency agreement with regard to St. Louis State Hospital and Missouri Rehabilitation Center. The council newsletter, *Quarterly,* features head injury programs and services, both private and state programs. During the annual conference, 26 exhibitors displayed information pertaining to their programs and several program providers presented during the conference. Council staff made presentations regarding services to the Missouri Head Injury Association Board of Directors on a regular basis, during the Association's annual conference, Missouri Association of Rehabilitation Facilities, St. Louis Mental Health Association, Missouri Association of County Developmental Disabilities Services, Missouri Coalition of Community Mental Health Centers and Missouri Planning Council for Developmental Disabilities.

Three-Year Goal: To develop programs which offer pre-vocational, vocational and/or vocational rehabilitation services.

First- through Third-Year Objectives **Fiscal Years 1990-1992**

Vocational Training

1. To encourage private/public institutions to develop vocational training programs for survivors of head injury.

2. Draft legislation, if needed, to allow state subsidy for those sheltered workshops who opt to provide training in addition to sheltered employment.

3. To determine the role of vocational education schools in providing vocational training to students who have suffered from a head injury.

Three-Year Goal: To determine appropriateness of sheltered employment for employees who are handicapped due to head injury.

First- through Third-Year Objectives **Fiscal Years 1990-1992**

1. Survey the number of persons with head injury in sheltered workshops.

2. Study the satisfaction of person with head injury, their families, and workshop managers with regard to appropriateness of sheltered employment.

Progress in Meeting FY'90-92 Objectives: During FY'88, Council staff served on the sheltered workshop advisory committee established by the Division of Special Education. The sheltered workshop managers suggested that the council develop a "white paper" outlining how the council believed sheltered employment should be made available to persons with head injury (setting, staffing, type of work, separate facilities, etc.). The council Committee on Program Planning and Development reviewed the types of sheltered employment (bench work model, enclave, mobile crew, etc.) and made some preliminary recommendations which have not yet been drafted for a paper. The council has favored the supported employment model.

Supported Employment

One-Year Goal: To develop supported employment programs.

Progress in Meeting FY'90 Objectives: During the summer of 1988, council staff met with the Governor's Core Policy Team on Supported Employment and the Team agreed that supported work would be beneficial to persons with head injury. Persons with head injury have been unable to access the supported work program as one of the federal requirements is that long-term support must be available. The Team wrote a letter supporting a budget request for the Office of Administration, Division of General Services, for long-term support programs to enable persons with head injury to participate in the supported work program. The Division of Vocational Rehabilita-

tion estimates that at least 30 clients could be served the first year. The Office of Administration, Division of General Services submitted a budget request which was agreed to by the Missouri General Assembly. Eight supported employment programs offering long-term support were started in FY'90.

Second-Year Objectives **Fiscal Year 1990**

1. Draft legislation, if needed, to address supported employment.
2. Work with the Division of Vocational Rehabilitation in accessing VR funds for supported employment for head injured clients.
3. Encourage the development of supported work programs.

Three-Year Goal: To develop employment opportunities.

Employment Opportunities

First- through Third-Year Objectives **Fiscal Years 1990-1992**

1. To determine vocational training and skills needed in order for survivors of head injury to become employable.
2. To evaluate success of persons with head injury in returning to employment.
3. To recognize employers who have established exemplary programs for employing persons with head injury.
4. To develop informational brochures for employers regarding the benefits of hiring persons handicapped due to head injuries.

Five-Year Goal:To establish day activity programs.

Day Activity Programs

First- through Fifth-Year Objectives **Fiscal Years 1990-1994**

1. Survey number of existing day programs or planned programs to be included in the service inventory/directory.
2. Determine need according to needs assessment.
3. Develop a model for day activity programs which address:

   (a) a definition/description of day activity programs including the qualifications of day program providers paid under state contract.

(b) an array of day program services which should be available according to needs assessment and registry data.

4. Explore funding for adult day care.

5. Work with the Department of Mental Health to develop day care, personal care, respite and home/equipment modification under the Medicaid waiver.

6. Prepare and submit budget requests to expand day programs and other support services.

Progress in Meeting FY'90 Objectives: A budget request was submitted for FY'90 for support services (community re-entry).

Issue 4: Services for Children

Background

Traumatic head injury is a major cause of disabilities in children. It was widely believed in the past that recovery after head injury is better in children than adults. Some studies now are disputing that notion. Problems following head injury may include overactivity, restlessness, agitation, aggression, impulsiveness, socially uninhibited behaviors, and/or fatigue. Traumatic brain injury impacts the family. Few resources are available to families to assist them in the home, to provide relief or respite, or to provide financial assistance.

Rehabilitation services for children are limited. Very few services are available to children with long-term medical needs. Developmental disability programs restrict eligibility often through IQ requirements. For school aged children the public school is often looked to to provide therapies which may be needed.

The Medicaid program, Early and Periodic Screening, Diagnosis and Treatment Program, has been expanded at the federal level and mandates states to provide services as noted in the assessment of a child even if the services which are allowed under the federal program are not an optional program under the state Medicaid Plan.

The Missouri Department of Mental Health, Division of Mental Retardation and Developmental Disabilities, provides some services to children with head injuries and their families. The division considers a child to be developmentally disabled when the injury occurs prior to age 22 and the child functions similarly to those children with mental retardation or other developmental disabilities. The division may offer case management and respite services for children who qualify, however, the division is reluctant to pay for medical or rehabilitation services associated with injury or to provide counseling or other family support services.

The Bureau of Special Needs, formerly the Crippled Children's Services, pays for some rehabilitation, however, the program will not cover services of a psychologists or cognitive re-training.

Accomplishments

The Missouri Department of Elementary and Secondary Education, Division of Special Education, has assigned staff to assist school districts to provide educational services to children with head injuries. The division has prepared a manual, *Developing Individual Education Plans for Students Who Have Suffered Traumatic Head Injury*, to be used in conjunction with the educator's manual prepared by the National Head Injury Foundation. The Missouri Division of Special Education has made the National Head Injury Foundation manual available to teachers upon request and encourages special educators to used the division's manual as a supplement. Films and other materials on head injury have been added to the Special Education Dissemination Center, University of Missouri-Columbia, a resource center for teachers and school administrators in Missouri who serve handicapped children.

Legislation, which passed during the 1988 legislative session, allows for the establishment of nursing homes for children under the state Medicaid program. The legislation also expands Medicaid eligibility for children.

The Department of Mental Health received approval for a Medicaid wavier which will allow reimbursement under the Medicaid program for community services for eligible or potential clients of the Division of Mental Retardation and Developmental Disabilities—including those who meet the division's eligibility requirements as the result of head injury. The waiver will include all ages provided they can also meet Medicaid eligibility.

Plan Initiatives

Four-Year Goal: To study and recommend appropriate rehabilitation, long-term care, educational, respite and other support services for children with head injuries and their families.

Rehabilitation, Education, Family Supports

First- through Four-Year Objectives **Fiscal Years 1990-1993**

1. Study and recommend a model(s) for programs for children suffering from head injury.
2. Work with the Department of Mental Health, Department of Elementary and Secondary Education and Department of Health to determine their roles in providing services to children with head injuries.
3. Work with the state agencies to determine the number of school age children with head injuries.

Progress In Meeting FY'90 Objectives: The council continues to work with the Department of Mental Health to determine its role and with the Department of Elementary and Secondary Education, Division of Special Education, on how to transition children from acute/rehabilitation facilities to school programs.

Issue 5: Residential Services/Supported Housing

Background

The goal of rehabilitation is to enable a person to return to his or her environment and to live as independently as possible. For those who are unable to live independently either within the family structure or alone, then some type of housing or support which provides supervision and protection may be needed. Others may require continued rehabilitation, medical, or specialized care provided in a residential setting. Residential settings which may be needed include nursing facilities, structured residential placement for those exhibiting severe behavior problems and supervised living arrangements.

For others to live independently some assistance may be required such as personal care assistance, in-home support, or home health care assistance. A family may need the benefit of respite care in order to maintain a family member with a head injury at home. Respite care provides temporary relief or emergency relief to the family, thus enabling the family to care for the person at home.

Long-term housing and housing support have yet to be developed specifically for survivors of head injury, although some supported housing is being provided to persons with head injury in one area of the state. The funding for that particular program is being provided by the Division of Comprehensive Psychiatric Services. Some individuals with head injury have been placed in community based residential facilities for persons with developmental disabilities, are in nursing homes, and habilitation centers and hospitals operated by the Department of Mental Health.

Accomplishments

During the FY'86, the Missouri Head Injury Advisory Council surveyed the number of survivors of head injury receiving services from the Department of Mental Health through its Divisions of Comprehensive Psychiatric Services and Mental Retardation and Developmental Disabilities, nursing homes and from home health care agencies. The survey noted that a significant number were being served, although most were not receiving services specific to their injury related deficits.

The Department of Mental Health is proposing to include eligible head injury clients receiving services from the Division of Mental Retardation and Developmental Disabilities under a Medicaid waiver in an attempt to provide services more appropriately and in a less restrictive environment. Services proposed under the waiver include residential, respite, and home adaptation.

St. Louis State Hospital, a psychiatric facility operated by the Department of Mental Health, has established a unit for persons with head injury who also have severe behavior problems. The council has supported funding for the unit and has encourage the department to coordinate services with the Missouri Rehabilitation Center operated by the Department of Health. The Missouri Rehabilitation Center received funding for four beds for severe behavior during the 1989 legislative session.

Some nursing facilities have expressed interest in serving head injured persons who are comatose, semi-comatose or who have extensive medical needs, however, the state Medicaid reimbursement rate does not accommodate the costs of serving such persons

The Office of Administration, Division of General Services, contracts for some in home support services.

Plan Initiatives

Two-Year Goal:Participate with the Department of Mental Health to implement a community based Medicaid waiver, which includes housing and community supports.

MR-DD Community Based Medicaid Waiver

Second-Year Objectives **Fiscal Year 1990**

1. Assist the Division of Mental Retardation and Developmental Disabilities by providing/arranging training to case managers with regard to evaluation/ assessment, interpretation, and writing appropriate rehabilitation/treatment goals.

Progress In Meeting FY'90 Objectives: Staff met presented information on head injury and services available to case managers at one regional center for the developmentally disabled. The Division fo Mental Retardation and Developmental Disabilities central office continued to identify the number of persons with head injury eligible for waiver services and to determine what their needs are.

Two Year Goal: To develop coma and semi-coma management programs.

Coma Management

First-Year Objectives **Fiscal Year 1990**

1. Survey and/or use registry data to determine the number of persons requiring coma/semi-coma care.

2. Support the Missouri Rehabilitation Center in developing either a coma or semi-coma management program.

3. Initiate a committee or task force to study the costs of coma management programs.

4. The committee once appointed, will study the necessary staffing and medical/ equipment considerations for a coma management program.

5. The committee will look at existing rate structure under the Medicaid program, the Medicaid exception process, Medicaid waiver or other funding areas and make recommendations as to how coma/semi-coma management programs should be funded.

Progress In Meeting FY'90 Objectives: The council chairman asked the Program Planning and Development Subcommittee on Long-Term Care to study this issue.

Second-Year Objectives **Fiscal Year 1991**

1. Introduce legislation, if needed, to implement coma/semi-coma management or other medically/rehabilitative intensive programs.

2. Develop standards, if needed, for the above programs.

3. Working with nursing home organizations, assist with staff training, if desired.

Behavior Management Programs

Three-Year Goal: To develop behavior management programs.

First-Year Objectives **Fiscal Year 1990**

1. Determine the need for a structured residential placement to be developed specifically for those with severe behavior problems.

2. Identify program costs needed for a program for severe behavior disorders.

Progress in Meeting FY'90 Objectives: The council supported the Department of Health budget item for the Missouri Rehabilitation Center for four bed for severe behavior disorders.

Second-Year Objectives **Fiscal Year 1991**

1. Identify eligibility criteria for those programs.

2. Identify potential providers for a behavior management programs.

3. Work with the University of Missouri-Columbia to develop in-service staff training workshop(s) designed to assist program (state and non-state) staff in managing aggressive behavior exhibited by head injured clients.

Third-Year Objectives **Fiscal Year 1992**

1. Prepare and submit a budget request to increase state funding for a pilot behavior management program.

Supervised Living/Supported Housing

Five-Year Goal:To develop supervised living arrangements for those who will continue to need supervision following rehabilitation.

First- and Second-Year Objectives **Fiscal Years 1990-1991**

1. To develop a model for supervised living arrangements addressing:

   (a) a definition/description of supervised living arrangements (apartment, group home), including staff requirements or other requirements.

   (b) an array of support services, including day programs or employment needed in conjunction with supervised living arrangements.

(c) standards, including physical plant facility, safety, drugs and medications, record keeping and client rights.

2. To study similar residential alternatives available to persons with head injury in other states and similar programs offered to other population groups in Missouri.

3. Determine the number of persons with head injury who are in need of supervised residential programs.

Third-Year Objectives **Fiscal Year 1992**

1. Study and recommend how supervised/supported living arrangements could be funded, both start up costs and operational costs.

2. Conduct a workshop on funding sources (HUD, Section 8, "S.B. 40", insurance and other sources) for supervised living arrangements.

Third- through Fifth-Year Objectives **Fiscal Years 1992-1994**

Supervised Living/Supported Housing

1. Locate potential providers for developing supervised living arrangements.

2. Assist potential providers in accessing funds.

3. Prepare and submit budget request to assist with funding for supervised residential programs.

Progress in Meeting FY'90 Objective: The council chairman directed the Program Planning and Development Subcommittee on Community Residential/Employment and Support Services to study and making recommendations for housing. The Committee, which also includes the director of the Missouri Head Injury Association, planned a meeting in St. Louis to allow input from families, drafted a housing questionnaire and has planned a workshop on housing options for fall 1990.

Home Health Care & Personal Care Assistance

Three-Year Goal: To expand usage of home health care and personal care attendant services.

First-Year Objective **Fiscal Year 1990**

1. To work with the Department of Mental Health to identify vendors who could provide home health care under the Medicaid waiver to clients with head injury.

Progress in Meeting FY'90 Objective: This objective has yet to be met.

Second-Year Objectives **Fiscal Year 1991**

1. To work with the Division of Vocational Rehabilitation to determine the number of persons with head injury who would be eligible for personal care assistance.

2. To work with the Division of Aging to determine how survivors of head injuries and their families could access home health care services through the division's programs.

3. Ask Missouri Association of Home Health Care Agencies and Hospital Home Health Council to include a session on the needs of persons with head injuries and their families at their annual conferences.

Third-Year Objectives **Fiscal Year 1991**

1. Based on needs on survivors of head injury for personal care assistance, work with the Division of Vocational Rehabilitation to obtain sufficient funding.

2. To develop a referral mechanism or resource document to include home health care agencies which could provide services to survivors of head injury and their families for hospitals, local health units, and physicians.

Respite Care

Three-Year Goal: To develop respite care.

First- through Third-Year Objectives **Fiscal Years 1990-1993**

1. To study various methods for providing respite care.

2. To study funding sources for respite care.

3. To develop a model for providing respite care.

4. To encourage providers to offer respite programs.

Support Services

Five-Year Goal:To develop an array of family support services and support services for individuals with traumatic head injury.

First- through Fifth-Year Objectives **Fiscal Years 1990-1994**

1. To design an array of family support services to include, but not limited to, information and referral, counseling, evaluation, crisis stabilization, in-home rehabilitation, recreation and transportation.

2. To identify potential providers for various family support services.

3. To develop resources for alcohol and drug treatment for persons with head injury.

Issue 6: Professional Training/Staff Development

Background

The demand for professionals experienced in working with survivors of head injury and their families will increase as programs and services are developed. Professionals will be needed in all areas including evaluation, case management, counseling, rehabilitation, community support programs and specialized programs such as behavior and coma management.

The Missouri Head Injury Advisory Council; Missouri Head Injury Association; Rehabilitation Institute, Kansas City; University of Missouri Health Sciences Continuing Education,Columbia; University of Missouri Rehabilitation Continuing Education Program and others have over the past few years sponsored statewide conferences for professionals and parents.

Accomplishments

The Missouri Head Injury Advisory Council has sponsored five statewide conferences which included sessions designed for professionals as well as families and other interested persons. In addition, the council sponsored a two-day workshop on supported work in 1989, and has planned a workshop on supported housing for 1990.

The Division of Vocational Rehabilitation has conducted several seminars for its counselors relating to head injury. The council, Division of Vocational Education and University of Missouri Rehabilitation Continuing Education Program have planned an in-service training workshop for vocational rehabilitation counselors, supported work and long-term support providers for October 1989.

The Division of Special Education has assigned staff to work with school districts and teachers who have students with head injury. The division provides assistance to help teachers to develop appropriate educational plans based on evaluations. The Department of Mental Health, Division of Mental Retardation and Developmental Disabilities, has agreed to work with the council to schedule an in-service training on evaluation and development of treatment plans for staff from the regional centers on developmental disabilities.

Plan Initiatives

Five-Year Goal: Provide opportunities for professionals to expand knowledge on head injury rehabilitation.

Professional Education Seminars

First- Through Fifth-Year Objectives **Fiscal Years 1990-1994**

1. Conduct a spring conference to include topics such as research, medical, rehabilitation and community re-entry.

2. Work with the Department of Mental Health to assess in-service needs of mental health and mental retardation and developmental disabilities staff.

3. Conduct an in-service training workshop for vocational rehabilitation specialists, supported work providers and long-term support work providers during FY'90.

4. Support the University of Missouri in efforts to obtain training funds to in-service staff providing services to persons with head injury.

Progress in Meeting FY'90 Objectives: The council held its annual conference May 21-23 in Jefferson City. Approximately 150 persons attended. The council sponsored in cooperation with the Division of Vocational Rehabilitation and the University of Missouri Rehabilitation Continuing Education Program an in-service training workshop on supported work for persons with head injury.

Functional Assessment

Two-Year Goal: To encourage assessment teams to use functional evaluation tools with neuropsychological and medical assessment.

First- and Second-Year Objectives **Fiscal Years 1990-1991**

1. To study and recommend the development of an evaluation tool to assess the functioning level of a persons with a head injury.

2. Support in-service training/conference(s) to assist staff on how to assess functional level.

Progress in Meeting FY'90 Objectives: This goal has yet to be realized and the council will continue to work on this goal.

Three-Year Goal: To train staff as to how to manage behavior problems.

First- through Third-Year Objectives **Fiscal Years 1990-1992**

1. To work with the University of Missouri-Columbia and/or other institutions to develop training packages for staff.

2. To conduct in-service workshops on behavior management.

Issue 7: Legal Issues

Background

As treatment, rehabilitation and other services for survivors of head injury are relatively new, many professionals, including the legal community, do not understand the deficits—such as cognitive, memory and judgment—that a survivor of head injury may have. Such deficits may pose problems for head injured persons who are trying to meet the demands of daily living.

Sometimes the rehabilitation and care of a person with a head injury are often determined by the amount the person receives through a settlement related to the injury. It is important, therefore, for those representing the survivor to understand the rehabilitative and, perhaps, the long-term care needs a person may have as the result of the injury.

Although certain types of disability or illness are addressed by law with regard to criminal actions, disabilities due to head injury are not. Persons considered dangerous to self or others may be involuntarily committed for psychiatric care if they are mentally disordered as defined by law or an alcohol or substance abuser as defined by law. A person suffering from a head injury who exhibits behavior which may be considered dangerous to self or others may be detained involuntarily under the provisions stated above for 96 hours. The mental health commitment law, however, does not pertain to persons who may be dangerous as the result of a brain injury. They cannot be detained beyond 96-hours unless they are determined to be mentally ill.

Another legal issue is the "right to die" issue. There are some instances where as the result of a severe head injury a person will remain in a vegetative state. Some parents or a spouse face a situation where the person will not regain conscious and is dependent on mechanical devices or feeding tubes to sustain life. Missouri does not have a "right to die" statute. The U.S. Supreme Court has agreed to review a case involving the disconnection of a feeding tube from a person with a head injury who is in a coma at the Missouri Rehabilitation Center.

Finally, some survivors of head injury may need protection or assistance in managing their fiscal affairs and/or personal affairs. It is important that the legal community understands how such protection could be provided under Missouri's Guardianship Code by a guardian or limited guardianship and/or a conservator or partial conservatorship.

Family members and other care givers need to understand the laws, as well, as they pertain to survivors of head injury.

Accomplishments

During the 1987-1990 conferences, workshops on legal issues were offered. Topics included Missouri's Guardianship Code, involuntary detention, "right to die" and criminal law. The Missouri Bar Association has offered to sponsor a seminar on head injury through its continuing education program. The Missouri Association of Trial Attorneys held seminars on head injury in Kansas City and St. Louis for attorneys for the fall of 1989. The council furnished a packet on services.

Plan Initiatives

Two-Year Goal: To develop appropriate programs for those persons suffering from a head injury considered dangerous to self or others.

Commitment Statutes

First- through Second-Year Objectives — **Fiscal Years 1990-1991**

1. Work with the Division of Comprehensive Psychiatric Services, Department of Mental Health, to determine appropriateness of the commitment statutes and the Department of Mental Health programs to serve persons with head injury considered dangerous to self or others.

2. Determine the number of persons who would require this type of care and protection.

Progress in Meeting FY'90 Objectives: Staff from the Department of Mental Health, Division of Comprehensive Psychiatric Services have met with the council to discuss in particular the role of St. Louis State Hospital and included head injury in the state mental health plan.

Two-Year Goal: To propose "right to die" legislation for introduction.

"Right to Die" Issues

First- throughSecond-Year Objectives — **Fiscal Years 1990-1991**

1. To study legislation from other state regarding the "right to die" issue.

2. To determine other organizations and professional groups which would also be interested in the "right to die" issue.

3. Draft legislation regarding the "right to die" concept.

4. Participate on the Task Force on Ethical Decision Making in Long-Term Care Facilities established by the Division of Aging.

Progress in Meeting FY'90 Objectives: The council supported legislation which would have allowed a person to designate a person to speak on his or behalf with regard to medical decisions to prolong life in the event the person is unable to make that decision due to his or her medical condition. The legislation failed to make it out of committee. The council staff participated on the Task Force on Ethical Decision Making in Long-Term Care Facilities established by the Division of Aging.

Three-Year Goal: To educate the legal system.

First- through Third-Year Objectives **Fiscal Years 1990-1992**

1. To ask the Missouri Association of Trial Attorneys to include a session(s) on head injury, at its annual conference.

2. To ask the Missouri Bar Association to include a seminar(s) on head injury through its continuing education program.

Progress in Meeting FY'90-92 Objectives: The Missouri Bar Association has agreed to sponsor a seminar. The Missouri Association of Trial Attorneys on its own is sponsoring seminars. The council staff gave a presentation at the state municipal judges conference in 1990.

Issue 8: Quality Assurance

Background

Since programs for survivors of head injury are relatively new, there are no state licensure or certification requirements for programs serving exclusively persons with head injury. (There are licensure/certification requirements for nursing homes and residential and day programs serving persons with mental illness, alcohol and drug abuse problems, mental retardation or other developmental disabilities.) The Commission on Accreditation of Rehabilitation Facilities (CARF), which is a voluntary organization, has developed accreditation standards for acute rehabilitation programs. The National Head Injury Foundation is an associate member of CARF.

Accomplishments

During FY'86, the council defined acute, functional and transitional living programs based, in part, on CARF standards. These definitions along with some fire and safety standards taken from the Department of Mental Health licensure standards were incorporated in the Request for Proposals issued by the Division of Purchasing and are a part of the contracts the Office of Administration, Division of General Services, have with agencies providing services to persons with head injury. During the 1988 May conference, a featured speaker addressed programs standards and the standards developed by CARF.

	Plan Initiatives
Program Standards	**Four-Year Goal:To develop standards for head injury programs receiving state funds.**
	First- through Fourth-Year Objectives — **Fiscal Years 1990-1993** 1. Study and make recommendations for program standards with regard to staffing, safety and treatment/ rehabilitation plans, 2. As standards are developed and are accepted, incorporate them into state program contracts (RFPs). ***Progress in Meeting FY'89-92 Objectives:*** Some program definitions and safety standards were incorporated in the RFPs issued for FY'89.

Issue 9: Financial Support

Background

Head trauma usually results in large medical bills particularly if the person is hospitalized extensively and/ or requires long term rehabilitation and care. Private insurance pays for at least partial acute care medical expenses. Many policies, however, do not cover rehabilitation, long term care, or complete hospital coverage. The state Medicaid program has strict financial guidelines which make it difficult for working families to be eligible. The program also is limited as to what services it will reimburse, and is particularly limited in reimbursing outpatient rehabilitation.

Some financial aid is available through Missouri Crippled Children's Services administered by the Missouri

Department of Health. The program is to help financially eligible children under 21 obtain medical, rehabilitation and other services. The guidelines are broad enough to accommodate children with head injuries, but program funding is limited. The program has also been reluctant to fund psychological and cognitive rehabilitation. If a person can meet the eligibility requirements of the Department of Mental Retardation, Division of Mental Retardation and Developmental Disabilities, some services are available through the eleven regional centers for developmental disabilities.

There are three issues surrounding insurance. One issue is that many persons did not carry health care insurance prior to the injury. Therefore, many persons, particularly young adults, do not have insurance to pay for their medical care. Others may carry insurance, but find that their policies do not cover rehabilitation (outpatient) and/or long term care. A third issue is that some survivors of head injury find that following their accidents, they are unable to find affordable health insurance as they are considered "high risk".

The costs associated with medial and long-term care will often place financial hardship on families who have a member with a brain injury. Should a person not have insurance or should the insurance not cover all expenses and the persons or family does not qualify for Medicaid, there are not any state aid programs to assist with the medical expenses. The only state funded programs specifically for persons with head injury are through the Missouri Rehabilitation Center operated by the Missouri Department of Mental Health and through contracts with the Missouri Office of Administration, Division of General Services, and community agencies.

A Missouri House of Representatives committee studies health care issues during the interim in 1986. It recommended a "MedAssist" program to help those who were unable to obtain insurance to have a health care plan. During the 1987 summer interim, a joint legislative committee held hearings to address health care issues and issued a report. Legislation was introduced in the 1988 session for the third year to establish a health insurance program. The legislation did not pass. During the 1988 session, legislation was introduced and failed. A voter referendum also failed.

Also, for at least four years legislation has been introduced to create a "high risk"pool in order for those considered "high risk" to be able to obtain insurance. The MedAssist concept and the high risk pool concept have been incorporated into an initiative petition calling for a constitutional amendment to be voted on November 8.

There are several programs (federal, state and local) which are targeted, in part, to programs for persons with handicaps or directly to handicapped persons. Such programs include HUD (Housing and Urban Development), Section 8 rental subsidy, SSI, Missouri Elderly and Handicapped Transportation Assistance Program, federal Developmental Disabilities program, Vocational Rehabilitation, supported work program, and county mill tax programs for persons who are or otherwise handicapped or developmentally disabled. Most of these programs have yet to be tapped by persons who are disabled due to a head injury or by programs providing head injury services.

Accomplishments

Council members testified before the interim house committee on health care regarding the needs of survivors of head injury. The council supported legislation to create a high risk pool and initiated legislation to create a catastrophic fund. During the 1987 session, legislation was introduced to allow voters to increase cigarette taxes to be used for a state catastrophic fund. The proposal failed to receive approval from the

senate committee. A Senate Concurrent Resolution No. 6 passed during the 1987 session calling for a joint interim committee to study health care needs. The council staff represented the Office of Administration on the committee which was comprised of five senators, five representatives, public members and state agencies.

Senator Ed Dirck, council member, requested an Attorney General's opinion as to whether programs providing services to persons with head injuries would be eligible to receive funding from county boards which administer revenue generated from a county tax for persons with handicaps and developmental disabilities. The opinion was that the programs would be eligible. The opinion was sent to all county boards and sheltered workshops. During the 1988 session, Senator Dirck sponsored legislation which would clarify that persons with head injury would be eligible. The bill did not pass and drew opposition from the mental retardation advocates.

Also, during the 1988 session, legislation expanding the Medicaid program. The bill expanded services to include comprehensive day rehabilitation for post acute trauma patients, to allow for the establishment of nursing facilities for children and expanded eligibility requirements for children.

Legislation passed in 1989 establishing the Missouri Family Trust Fund allowing donors to establish an individual trust on behalf of person with disabilities. The Fund has been established in such a way that public benefits or entitlements which a beneficiary may receive are protected. The Family Trust Fund also provides for a Charitable Trust which can receive contributions on behalf of persons who do not have trusts established specifically for them by a donor.

Legislation passed in 1990 creating a high risk health insurance pool. Legislation also passed in 1990 expanding the definition for developmental disabilities which determines eligibility for services from the Division of Mental Retardation and Developmental Disabilities.

Plan Initiatives

Health Care Coverage

One-Year Goal: For survivors of head injury to be able to obtain health care coverage.

First-Year Objective **Fiscal Year 1990**

1. To continue to support efforts to create a high risk pool or any other alternative to allow persons considered high risk due to a head injury to obtain health care insurance (i.e. MedAssist).

Progress In Meeting FY'90 Objective: The council supported the risk risk pool legislation, which passed.

Three-Year Goal: To extend health insurance coverage.

First-Year Objectives **Fiscal Year 1990**

1. To study present required coverage under Missouri law.

2. To study other states' requirements for health care coverage.

Progress in Meeting FY'90 Objective: The council chairman appointed a council member who works for the Division of Insurance to serve as a liaison member on the Missouri Head Injury Association Insurance Task Force. The council staff attended a National Conference on Automobile Insurance Issues at the invitation of the Insurance Information Institute. The conference discussed costs savings measures including prevention and medical management of injuries. A session on insurance and other third party payers was featured during the 1990 conference.

Second-Year Objectives **Fiscal Year 1991**

1. To study and to assess cost savings, if any, if coverage were extended to include rehabilitation.
2. To study costs of including long term care coverage in health policies.
3. To study benefits of including catastrophic coverage in health policies.

Third-Year Objectives **Fiscal Year 1992**

1. To meet with the insurance industry to discuss rehabilitation coverage.
2. To meet with business associations and organizations to discuss cost and cost benefits, in any, for including rehabilitation coverage in group policies.

Two-Year Goal: To expand Medicaid coverage.

Expand Medicaid

First- through Second Year Objectives **Fiscal Years 1990-1991**

1. To study state and federal options under the Medicaid programs.
2. To make the legislators aware of the needs of survivors of head injury which could be addressed under the Medicaid program.
3. To recommend changes in the Medicaid program in order to meet the medical needs of survivors of head injury.
4. To study the feasibility of obtaining a Medicaid waiver to cover persons who are disabled due to head injures.
5. To work with the Senate Select Committee on Nursing Home Problems to develop recommendations for developing a rate reimbursement sufficient to cover persons with head injury who have acute medical and rehabilitation needs.

Progress in Meeting FY'90 Objectives: Council staff worked with the Department of Social Services, Division of Medical Services to develop a vendor manual and eligibility requirements for the new Medicaid service, comprehensive day rehabilitation service, which was added by way of legislation in 1988. Programs began enrolling in the Medicaid program to provide this service in January 1990.

Access to Local, State and Federal Programs and Funding

Two-Year Goal: To access local, state and federal programs for persons with disabilities.

First- and Second-Year Objective — **Fiscal Year 1990-1991**

1. To make available to organizations, agencies, and persons information regarding various programs through the newsletter, presentations, etc.

Progress in Meeting FY'90 Objectives: The council routinely provides such information via the newsletter, conferences, presentations, etc. A handbook produced by the Missouri Head Injury Association through a contract with the Missouri Office of Administration, Division of General Services, contained information on services and funding sources. The manual was distributed to families, rehabilitation providers, hospitals, and advocacy organizations.

First- and Second-Year Objectives — **Fiscal Years 1990-1991**

1. To sponsor workshop on funding resources, especially on HUD and Section 8 housing subsidy.

2. To meet with the state Disability Determination office and the Division of Family Services offices to discuss disability due to head injury.

3. Support federal funding for head injury prevention, rehabilitation and long-term care.

Progress in Meeting FY'90 Objectives: The council has worked with and supported the Department of Health and the University of Missouri-Columbia in their pursuit of various grants for prevention and rehabilitation projects. The Office of Administration submitted an application to the Rehabilitation Services Administration for a model systems grant in 1990. The RSA awarded four grants, but Missouri did not receive a grant. With the exception of the Centers for Disease Control grant most projects have failed to receive funding. During the council's fifth annual conference held May 1989, a panel representing federal programs presented information regarding programs and funding available through the different agencies.

The council is planning a workshop on supported housing including funding sources for fall 1990.

About the Missouri Head Injury Advisory Council

The Missouri Head Injury Advisory Council is to be comprised of twenty-five members of which twenty-one are appointed by the Governor with advice and consent of the Missouri Senate. The twenty-one members are to represent consumers, families with a member with a head injury, professionals, proprietary schools, private industry, health industry and state agencies which administer programs regarding education, mental health, health, Medicaid, insurance, and public safety. Four members represent the Missouri General Assembly of which two members are state representatives and are appointed by the Speaker of the House of Representatives for the remainder of their terms and two members are state senators appointed by the Senate President Pro-Tempore for the remainder of their terms.

The council members elect a chairman and vice chairman for a term on one year in September in accorance with the bylaws.

Judith A. Ferguson, Kimberling City, is chairman of the Missouri Head Injury Advisory Council. She is the founder of the Missouri Head Injury Association and is past vice president of State Association Affairs of the National Head Injury Foundation. She is a family member representative on the council having a son who suffered a head injury in 1978.

Representative Sheila Lumpe, University City, is vice chairman of the council. She served as a member of the Joint Interim Committee on Head Injury during the summer of 1984. During the 1986 legislative session, she sponsored legislation which created the head and spinal cord injury registry and established the Missouri Head Injury Advisory Council. She serves as vice chairman of the House Committee on Critical Decisions and of the House Elementary and Secondary Education Committee and as a member of the House Ways and Means Committee and Budget Committee.

John F. Allan, Ed.D., Jefferson City, is the Assistant Commissioner (head) of the Division of Special Education, Department of Elementary and Secondary Education. In addition to assisting local school districts with the provision of services to handicapped children, the division is responsible for the state schools for the severely handicapped, state school for the blind, state school for the deaf, and administering the sheltered workshop subsidy. Dr. Allan is a member of the American Educational Research Association and has served as a consultant for the National Center for Educational Statistics.

Susan P. Bliss, Columbia, is an instructor in the College of Education, Special Education Department, University of Missouri-Columbia. She has served on the board of the Missouri Chapter of the National Head Injury Foundation (known as the Missouri Head Injury Association), as Mid-Missouri Chapter president and on numerous Association committees. Other professional memberships include Missouri Association for Children with Learning Disabilities, Council for Exceptional Children and American Society of Training and Development and the Missouri Chapter. She is the parent of a daughter who suffered a head injury in 1975. She was appointed April 1989.

Caroline A. Castillo, Kansas City, is employed at Counseling Consultants of Clinton. She received a Bachelor of Arts in Education in psychology in 1985 and a Master of Arts in counseling in 1989. She received a closed head injury in 1980.

Donald M. Claycomb, Ph.D., Jefferson City, is the Executive Director of the State Council on Vocational Education. He is a member of the Committee on Liaison to the National Councils on Vocational Education, National Association of State Councils on Vocational Education.

Senator Edwin L. Dirck, St. Ann, served as the first chairman of the council from 1985 to 1987. During the summer of 1984, he chaired a Joint Interim Committee on Head Injury which held a series of statewide public hearings. Following the hearings, he introduced and passed the mandatory seat belt law. He also sponsored and passed the legislation establishing and regulating trauma centers. He serves as chairman of the Senate Budget Control Committee, as vice chairman of the Senate Aging and Mental Health Committee and as chairman of the Legislative Research Committee. He also is a member of the Senate Insurance Committee and the Ways and Means Committee.

Ben H. Ernst, St. Louis, is the Director of the Rankin Technical Institute. He is past president of the Missouri Association of Private Career Schools and past president of the American Technical Educational Association. He serves as the Regional Representative of the American Technical Association; member of the American Vocational Association and is Financial Secretary to the Board of Trustees of Rankin Technical Institute. He resigned from the council January 1990.

R. Dale Findlay, Jefferson City, is the director of the Missouri Safety Council. He is past vice president of the Association of the Association of Safety Council Executives and is serving on the Governor's DWI Advisory Council. He is also a member of the Missouri Advisory Council on Alcohol and Drug Abuse and has been appointed to the Missouri Injury Control Advisory Committee.

Robert G. Frank, Ph.D, Columbia, is Associate Professor and Vice Chairman, Department of Physical Medicine and Rehabilitation, School of Medicine, University Hospital and Clinics, University of Missouri. Dr. Frank is a member of the Mid-Missouri Psychology Consortium Coordinating Committee.

Donald L. Gann, Ed.D., Assistant Commissioner (head) of the Division of Vocational Rehabilitation, Department of Elementary and Secondary Education. He is a member of the National Rehabilitation Association and the Council of State Administrators of Vocational Rehabilitation. He represented the Department of Elementary and Secondary Education on the Joint Interim Committee on Head Injury.

Charles H. Goforth, Springfield, is President and Administrator of UpJohn Health Care Services serving sixteen counties in Southwest Missouri. He is a member of the Missouri Advisory Council for Home Health Care.

William E. Hickle, J.D., Rolla, is an attorney with Carnahan, Carnahan and Hickle. He is a member of the Missouri Association of Trial Attorneys and the Missouri Bar Association. His law practice specializes in personal injury litigation, workers' compensation claims, guardianship and probate law.

L. Dennis Humphrey, Ed.D., Springfield, is a professor in the Department of Biomedical Sciences, Southwest Missouri State University. He is secretary of the Board of Directors, Springfield Coalition for Disability Rights. He is also a member of the Handicapped Advisory Committee, Mayor's Commission on Human Rights; of the Advisory Council of the Wollner Memorial Library; and past member of the Missouri Governor's Committee on Employment of the Handicapped.

Gerald J. Kampeter, Jefferson City, is the parent of a daughter with a head injury. He has worked for the Missouri Highway and Transportation Commission for over 35 years. He is active in the Highway and Transportation Employees Association and the Travelers Protective Association of America.

Nancy Koenig, Florissant, is the parent of a son who suffered a head injury. She has served as president of the St. Louis Bi-State Chapter of the Missouri Head Injury Association and as vice president of Operation of the Association. She is a retired elementary school music teacher.

Jane Y. Kruse, Jefferson City, is the director of the Division of Child Support Enforcement, Department of

Social Services. She is an attorney and a member of the Missouri Bar, Missouri Health Coordinating Council and the Alzheimer's Disease Task Force.

Donald E. McGowan, Wentzville, is safety director, BOC Group-General Motors Corporation, Wentzville Assembly Center. He is chairman of the Board of Directors of the Safety Council of Greater St. Louis and is past president of the board. He also served as a member of the Board of Directors of the Missouri Safety Council from 1980 to 1984. He resigned January 1990.

Representative Carole Roper Park, Sugar Creek, chairs the House Appropriations Committee on Health and Mental Health. She also serves on the House Budget Committee; Energy and Environment Committee; House Tourism, Recreational and Cultural Affairs Committee; and the House Ways and Means Committee. She is the recipient of various awards including the 1984 Distinguished Health Legislative Award by the Osteopathic Association. She is active in many organizations advocating for persons with developmental disabilities and persons with mental illness. Representative Park was appointed to the council by the Speaker of the House in March 1989.

Charles "Chuck" Renn, Jefferson City, is the Deputy Director, Company Regulations, Missouri Division of Insurance. He is a liaison member of the Missouri Head Injury Association Task Force on Insurance. He is also a member of the Alzheimers and Related Disorders Task Force.

C. Keith Schafer, Ed.D., Holts Summit, is the director of the Missouri Department of Mental Health. The department operates three service divisions: Division of Alcohol and Drug Abuse, Division of Mental Retardation and Developmental Disabilities, and the Division of Comprehensive Psychiatric Services. Dr. Schafer was appointed to the council in April 1989.

Nathan B. Walker, Jefferson City, is the director of the Division of Highway Safety, Department of Public Safety. He serves as Missouri's Governor's Representative to Highway Safety and is a member of the Governor's Council on DWI. He served two terms as state representative from 1980 to 1984. In 1982, he was elected as the Minority Whip of the House of Representatives.

C. Keith Whittaker, M.D., Kansas City, is a neurosurgeon at St. Luke's Hospital, Kansas City. He is a member of the American Medical Association, Missouri State Medical Society and American College of Surgeons. He is president of the Missouri Neurosurgical Society.

Senator Harry Wiggins, Kansas City, served as a member of the Joint Interim Committee on Head injury in 1984. He chairs the Senate Ways and Means Committee and serves as vice chairman of the Senate Judiciary and Public Health and Welfare Committees. He serves also on the Senate Appropriations Committee, Interstate Cooperation and Rules, Joint Rules & Resolutions Committees. He handled the house bill in the Senate which created the head and spinal cord injury registry. He was the sponsor of the senate version.

Lorna M. Wilson, R.N., C., MSPH, Jefferson City, is the director of the Division of Maternal, Child, and Family Health, Department of Health. The division operates the Missouri Rehabilitation Center which has a head injury unit. She is a member of the Missouri Nurses Association, American Nurses Association, Missouri Public Health Association and the Task Force for Local Health for State Board of Health.

About the Staff

Susan L. Vaughn, M.Ed, Jefferson City, is the director of the Missouri Head Injury Advisory Council. She has over fifteen years of experience in state government and eighteen years in the field of disabilities. She has previously been employed as a speech therapist at B.W. Sheperd State School for the Severely Handicapped, operated by the Missouri Department of Elementary and Secondary Education, as a regional coordinator of the Region IX Council on Developmental Disabilities, and as a program specialist (staff for the Missouri Planning Council for Developmental Disabilities) and as the assistant to the director of the Department of Mental Health in Jefferson City. She represented the Department of Mental Health on the Joint Interim Committee on Head Injury.

Lois M. Lorenz, Jefferson City, is the secretary for the head injury program. She has worked in state government of over eight years having worked for the Department of Mental Health both in the Division of Alcohol and Drug Abuse and for the department director's office. Prior to the department, she worked for the Office of Administration, Division of Personnel.